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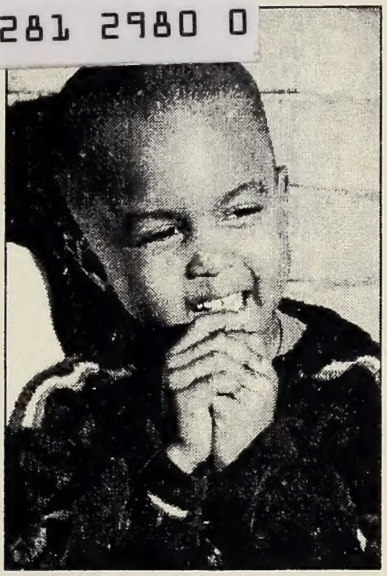
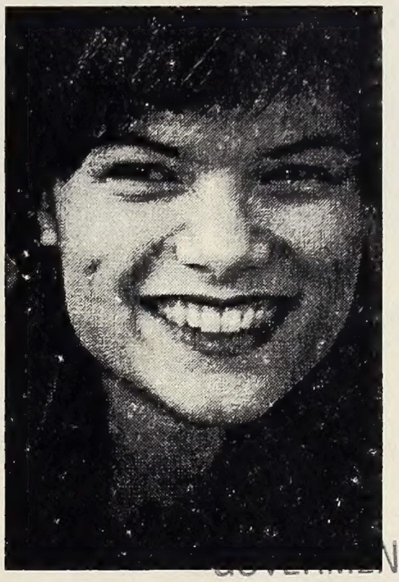
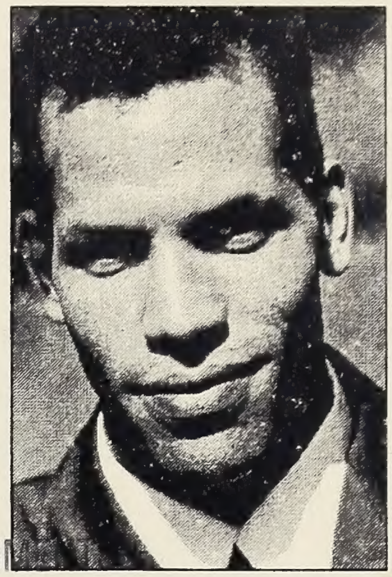

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COMMITTEE BRIEFING PACKET
Including Testimony and Material submitted Post-Hearing

Confronting Inequality:

Disparities in the Provision of Health Care Among Racial, Ethnic and Geographic Populations

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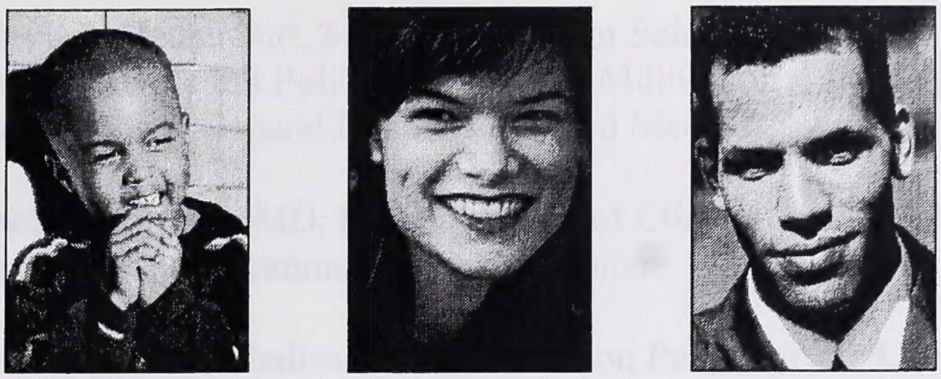
A Special Oversight Hearing of the Joint Committee on Health Care

Hearing Date: *June 4, 2002*
Updated with Submitted Material: *June 27, 2002*
State House, Boston

Senator Richard T. Moore, Senate Chairman
Representative Harriett L. Stanley, House Chairman



Confronting Inequality

A Special Oversight Hearing of the Joint Committee on Health Care

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Commissioner Howard Koh, MD, Department of Public Health

Commissioner Wendy Warring, Division of Medical Assistance

Charles A. Welch MD, Massachusetts Medical Society, President

Robert Gibbons, Massachusetts Hospital Association,

Julie Pinkham, Executive Director, MNA Massachusetts Nurses Association.

Prof. Thomas McGuire, Ph.D.
Professor of Health Economics, Harvard Medical School

Joseph R. Betancourt, MD, MPH, Senior Scientist,
Institute for Health Policy, Director for Multicultural Education,
Massachusetts General Hospital-Harvard Medical School

Giselle Thornhill, MD, MPH, Director of Clinical Health Affairs,
Mass League of Community Health Centers

John Rich, MD, Medical Director, Boston Public Health Commission

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3. Testimony of Joseph R. Betancourt, MD, MPH
4. Testimony of Gisele Thornhill, MD, MPH
5. Testimony and statistical material from John A. Rich, MD, MPH and an article from the American Journal of Public Health, *Levels of Racism: A Theoretic Framework and a Gardener's Tale*
6. The Middlesex County Alumnae Chapter of Delta Sigma Theta, submitted a copy of a resolution adopted by the Chapter. The resolution calls for the support of health and wellness programs for the African American community.

Confronting Inequality

A Special Oversight Hearing of the Joint Committee on Health Care

INTRODUCTION

In March of 2002 the National Academy of Science's Institute of Medicine released a pre-publication report titled, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care.* The report's conclusion: "racial and ethnic minorities tend to receive lower-quality health care than whites do, even when insurance status, income, age and severity of conditions are comparable" is, sadly, not considered surprising among health care researchers who have examined the issue. Nor is this conclusion surprising for a consistent reader of the Health/Science section of any of the Countries' major newspapers or magazines; for several years now studies reporting the particulars of disparate health care treatment have been reported by news organizations, medical journals and other publications. Despite the attention the issue intermittently receives however, a comprehensive public policy response involving the government, the private health care sector and health care researchers has not been explored. It is the Committee's hope that this oversight hearing will reveal several policy ideas—short term and long-term—that can be pursued by all constituencies working in concert.

The publication of *Unequal Treatment* is the result of a request from the U.S. Congress for a study by the Institute of Medicine that would reveal the extent of the health disparities and propose possible solutions. Actual publication of the full report will not occur until the end of June 2002 but the report and the executive summary are available online at the Institute of Medicine's website, www.iom.edu. The executive summary of *Unequal Treatment* is included in this briefing packet. However, one paragraph of the executive summary should be noted because it is a startling recitation of the extent of the problem. On page 3 of the summary the authors' write:

> A large body of published research reveals that racial and ethnic minorities experience a lower quality of health services, and are less likely to receive even routine medical procedures than are white Americans. Relative to whites, African Americans – and in some cases, Hispanics – are less likely to receive appropriate cardiac medication (e.g., Herholz et al., 1996) or to undergo coronary artery bypass surgery (e.g., Ayanian et. Al, 1993, Hannan et al, 1999; Johnson et al, 1993; Peterson et al., 2002), are less likely to receive hemodialysis and kidney transplantation (e.g., Epstein et al., 2000; Barker-Cummings et al., 1995; Gaylin et al, 1993), and are likely to receive a lower quality of basic clinical services (Ayanian et al., 1999) such as intensive care (Williams et al., 1995), even when variations in

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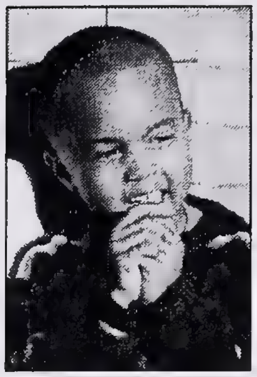
> such factors as insurance status, income, age, co-morbid conditions, and symptom expression are taken into account. Significantly, these differences are associated with greater mortality among African-American patients (Peterson et al., 1997; Bach et al., 1999)

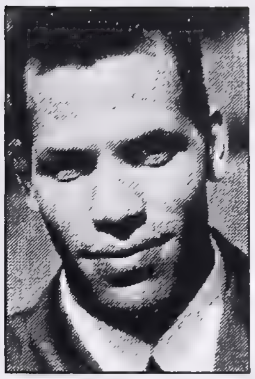
And research also suggests that disparate access to quality health care is not only associated with minority status; geographic location may also be an indicator of the level of care a patient receives. For example, a study by the Department of Public Health found that the rate of birth defects varies by region of the state, with the western region of the state experiencing a slightly higher rate of birth defects.

Within the literature included in this packet, the two most common suggestions for reducing the impact of race, ethnicity and location on health care outcomes are the increased collection of data to better target the problem and additional training of medical students to ensure that they are able to discern any bias or harmful preconceptions in their diagnoses or recommendations of treatment. These two proposals, data collection and cultural competence training, should, at a minimum, constitute the beginning of a response and it is the Committee's hope that this hearing will reveal additional solutions as well.

Confronting Inequality
A Special Oversight Hearing of the Joint Committee on Health Care

Selected Articles and Essays





Confronting Inequality

A Special Oversight Hearing of the Joint Committee on Health Care

Testimony and Material Submitted Post-Hearing

Abstract

Racial and ethnic minorities tend to receive a lower quality of healthcare than non-minorities, even when access-related factors, such as patients' insurance status and income, are controlled. The sources of these disparities are complex, are rooted in historic and contemporary inequities, and involve many participants at several levels, including health systems, their administrative and bureaucratic processes, utilization managers, healthcare professionals, and patients. Consistent with the charge, the study committee focused part of its analysis on the clinical encounter itself, and found evidence that stereotyping, biases, and uncertainty on the part of healthcare providers can all contribute to unequal treatment. The conditions in which many clinical encounters take place – characterized by high time pressure, cognitive complexity, and pressures for cost-containment – may enhance the likelihood that these processes will result in care poorly matched to minority patients' needs. Minorities may experience a range of other barriers to accessing care, even when insured at the same level as whites, including barriers of language, geography, and cultural familiarity. Further, financial and institutional arrangements of health systems, as well as the legal, regulatory, and policy environment in which they operate, may have disparate and negative effects on minorities' ability to attain quality care.

A comprehensive, multi-level strategy is needed to eliminate these disparities. Broad sectors – including healthcare providers, their patients, payors, health plan purchasers, and society at large – should be made aware of the healthcare gap between racial and ethnic groups in the United States. Health systems should base decisions about resource allocation on published clinical guidelines, insure that physician financial incentives do not disproportionately burden or restrict minority patients' access to care, and take other steps to improve access – including the provision of interpretation services, where community need exists. Economic incentives should be considered for practices that improve provider-patient communication and trust, and reward appropriate screening, preventive, and evidence-based clinical care. In addition, payment systems should avoid fragmentation of health plans along socioeconomic lines.

The healthcare workforce and its ability to deliver quality care for racial and ethnic minorities can be improved substantially by increasing the proportion of underrepresented U.S. racial and ethnic minorities among health professionals. In addition, both patients and providers can benefit from education. Patients can benefit from culturally appropriate education programs to improve their knowledge of how to access care and their ability to participate in clinical-decision making. The greater burden of education, however, lies with providers. Cross-cultural curricula should be integrated early into the training of future healthcare providers, and practical, case-based, rigorously evaluated training should persist through practitioner continuing educa-

tion programs. Finally, collection, reporting, and monitoring of patient care data by health plans and federal and state payors should be encouraged as a means to assess progress in eliminating disparities, to evaluate intervention efforts, and to assess potential civil rights violations.

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EXECUTIVE SUMMARY

Looking gaunt but determined, 59-year old Robert Tools was introduced on August 21, 2001 as a medical miracle – the first surviving recipient of a fully implantable artificial heart. At a news conference, Tools spoke with emotion about his second chance at life and the quality of his care. His physicians looked on with obvious affection, grateful and honored to have extended Tools' life. Mr. Tools has since lost his battle for life, but will be remembered as a hero for undergoing an experimental technology and paving the way for other patients to undergo the procedure. Moreover, the fact that Tools was African American and his doctors were white seemed, for most Americans, to symbolize the irrelevance of race in 2001. According to two recent polls, a significant majority of Americans believe that blacks like Tools receive the same quality of healthcare as whites (Lillie-Blanton et al., 2000; Morin, 2001).

Behind these perceptions, however, lies a sharply contrasting reality. A large body of published research reveals that racial and ethnic minorities experience a lower quality of health services, and are less likely to receive even routine medical procedures than are white Americans. Relative to whites, African Americans – and in some cases, Hispanics – are less likely to receive appropriate cardiac medication (e.g., Herholz et al., 1996) or to undergo coronary artery bypass surgery (e.g., Ayanian et al., 1993, Hannan et al., 1999; Johnson et al., 1993; Petersen et al., 2002), are less likely to receive hemodialysis and kidney transplantation (e.g., Epstein et al., 2000; Barker-Cummings et al., 1995; Gaylin et al, 1993), and are likely to receive a lower quality of basic clinical services (Ayanian et al., 1999) such as intensive care (Williams et al., 1995), even when variations in such factors as insurance status, income, age, co-morbid conditions, and symptom expression are taken into account. Significantly, these differences are associated with greater mortality among African-American patients (Peterson et al., 1997; Bach et al., 1999).

STUDY CHARGE AND COMMMITTEE ASSUMPTIONS

These disparities prompted Congress to request an Institute of Medicine (IOM) study to assess differences in the kinds and quality of healthcare received by U.S. racial and ethnic minorities and non-minorities. Specifically, Congress requested that the IOM:

- Assess the extent of racial and ethnic differences in healthcare that are not otherwise attributable to known factors such as access to care (e.g., ability to pay or insurance coverage);
- Evaluate potential sources of racial and ethnic disparities in healthcare, including the role of bias, discrimination, and stereotyping at the individual (provider and patient), institutional, and health system levels; and,
- Provide recommendations regarding interventions to eliminate healthcare disparities.

This Executive Summary presents only abbreviated versions of the study committee's findings and recommendations. For the full findings and recommendations, and a more extensive justification of each, the reader is referred to the committee report. Below, findings and recommendations are preceded by text summarizing the evidence base from which they are drawn. For purposes of clarity, some findings and recommendations are presented in a different sequence than they appear in the full report; however, their numeric designation remains the same.

Defining Racial and Ethnic Healthcare Disparities

The study committee defines *disparities* in healthcare as racial or ethnic differences in the quality of healthcare that are not due to access-related factors or clinical needs, preferences[1], and appropriateness of intervention (Figure 1). The committee's analysis is focused at two levels: 1) the operation of healthcare systems and the legal and regulatory climate in which health systems function; and, 2) discrimination at the individual, patient-provider level. Discrimination, as the committee uses the term, refers to differences in care that result from biases, prejudices,

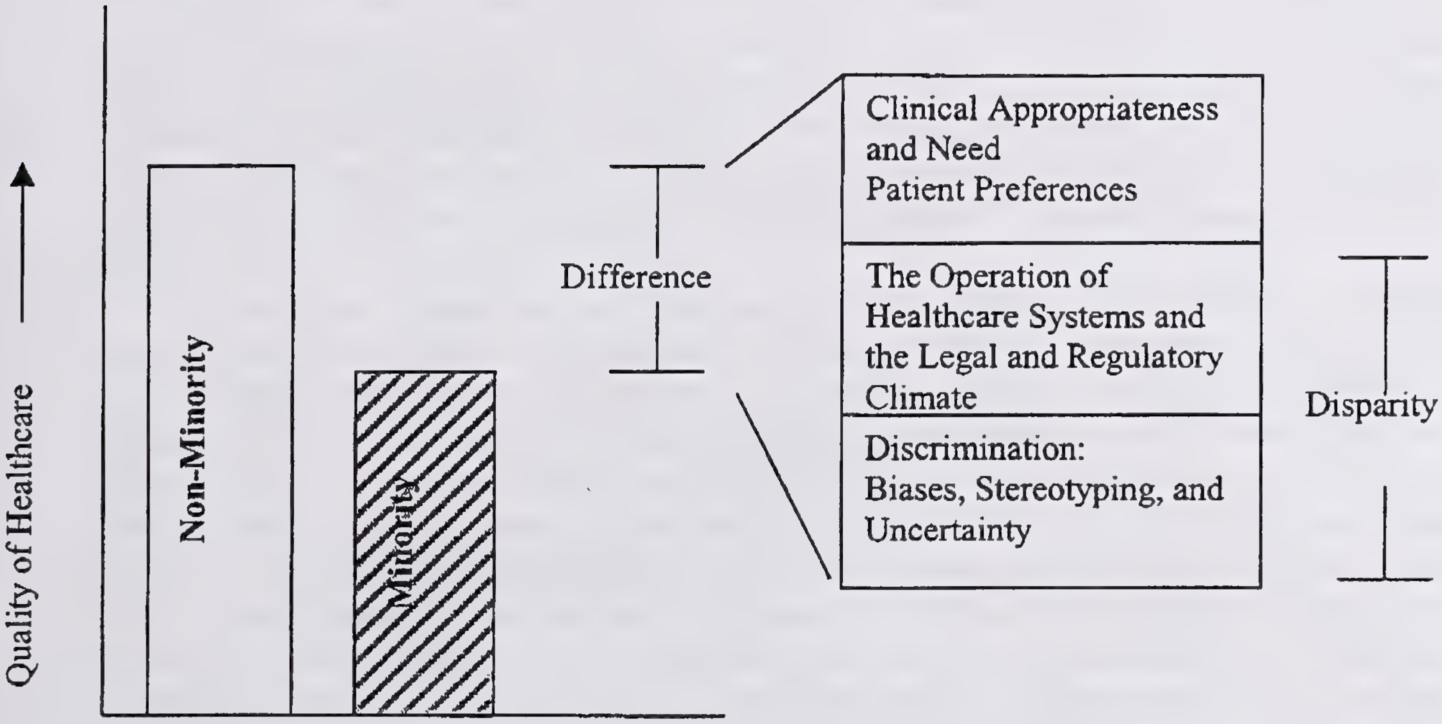
Quality of Healthcare
Non-Minority
Minority
Difference
Clinical Appropriateness and Need
Patient Preferences
The Operation of Healthcare Systems and the Legal and Regulatory Climate
Discrimination: Biases, Stereotyping, and Uncertainty
Disparity

Figure 1-1 Differences, Disparities, and Discrimination: Populations with Equal Access to Healthcare. Source: Gomes and McGuire, 2001

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[1] The committee defines patient *preferences* as patients' choices regarding healthcare that are based on a full and accurate understanding of treatment options. As discussed in Chapter 3 of this report, patients' understanding of treatment options is often shaped by the quality and content of provider-patient communication, which in turn may be influenced by factors correlated with patients' and providers' race, ethnicity, and culture. Patient preferences that are not based on a full and accurate understanding of treatment options may therefore be a source of racial and ethnic disparities in care. The committee recognizes that patients' preferences and clinicians' presentation of clinical information and alternatives influence each other, but found separation of the two to be analytically useful.

stereotyping, and uncertainty in clinical communication and decision-making. It should be emphasized that these definitions are not legal definitions. Different sources of federal, state and international law define discrimination in varying ways, with some focusing on intent and others emphasizing disparate impact.

EVIDENCE OF HEALTHCARE DISPARITIES

Evidence of racial and ethnic disparities in healthcare is, with few exceptions, remarkably consistent across a range of illnesses and healthcare services. These disparities are associated with socioeconomic differences and tend to diminish significantly, and in a few cases, disappear altogether when socioeconomic factors are controlled. The majority of studies, however, find that racial and ethnic disparities remain even after adjustment for socioeconomic differences and other healthcare access-related factors (for more extensive reviews of this literature, see Kressin and Petersen, 2001; Geiger, this volume; and Mayberry, Mili, and Ofili, 2000).

Studies of racial and ethnic differences in cardiovascular care provide some of the most convincing evidence of healthcare disparities. The most rigorous studies in this area assess both potential underuse and overuse of services and appropriateness of care by controlling for disease severity using well-established clinical and diagnostic criteria (e.g., Schneider et al, 2001; Ayanian et al., 1993; Allison et al., 1996; Weitzman et al., 1997) or matched patient controls (Giles et al., 1995). Several studies, for example, have assessed differences in treatment regimen following coronary angiography, a key diagnostic procedure. These studies have demonstrated that differences in treatment are not due to clinical factors such as racial differences in the severity of coronary disease or overuse of services by whites (e.g., Schneider et al, 2001; Laouri et al., 1997; Canto et al., 2000; Peterson et al., 1997). Further, racial disparities in receipt of coronary revascularization procedures are associated with higher mortality among African Americans (Peterson et al., 1997).

Healthcare disparities are also found in other disease areas. Several studies demonstrate significant racial differences in the receipt of appropriate cancer diagnostic tests (e.g., McMahon et al., 1999), treatments (e.g., Imperato et al., 1996), and analgesics (e.g., Bernabei et al., 1998), while controlling for stage of cancer at diagnosis and other clinical factors. As is the case in studies of cardiovascular disease, evidence suggests that disparities in cancer care are associated with higher death rates among minorities (Bach et al. 1999). Similarly, African Americans with HIV infection are less likely than non-minorities to receive antiretroviral therapy (Moore et al., 1994), prophylaxis for pneumocystis pneumonia, and protease inhibitors (Shapiro et al., 1999). These disparities remain even after adjusting for age, gender, education, CD4 cell count, and insurance coverage (e.g., Shapiro et al., 1999). In addition, differences in the quality of HIV care are associated with poorer survival rates among minorities, even at equivalent levels of access to care (Bennett et al., 1995; Cunningham et al., 2000).

Racial and ethnic disparities are found in a range of other disease and health service categories, including diabetes care (e.g., Chin, Zhang, and Merrell, 1998), end-stage renal disease and kidney transplantation (e.g., Epstein et al., 2000; Kasiske, London, and Ellison, 1998; Barker-Cummings et al., 1995; Ayanian et al., 1999), pediatric care and maternal and child health, mental health, rehabilitative and nursing home services, and many surgical procedures. In some instances, minorities are *more* likely to receive certain procedures. As in the case of bilateral orchiectomy and amputation, however (which African Americans undergo at rates 2.4 and

3.6 times greater, respectively, than their white Medicare peers; Gornick et al, 1996), these are generally less desirable procedures.

Finding 1-1: Racial and ethnic disparities in healthcare exist and, because they are associated with worse outcomes in many cases, are unacceptable.

Recommendation 2-1: Increase awareness of racial and ethnic disparities in healthcare among the general public and key stakeholders.

Recommendation 2-2: Increase healthcare providers' awareness of disparities.

RACIAL ATTITUDES AND DISCRIMINATION IN THE UNITED STATES

By way of context, it is important to note that racial and ethnic disparities are found in many sectors of American life. African Americans, Hispanics, American Indians, and Pacific Islanders, and some Asian-American subgroups are disproportionately represented in the lower socioeconomic ranks, in lower quality schools, and in poorer-paying jobs. These disparities can be traced to many factors, including historic patterns of legalized segregation and discrimination. Unfortunately, some discrimination remains. For example, audit studies of mortgage lending, housing, and employment practices using paired "testers" demonstrate persistent discrimination against African Americans and Hispanics. These studies illustrate that much of American social and economic life remains ordered by race and ethnicity, with minorities disadvantaged relative to whites. In addition, these findings suggest that minorities' experiences in the world outside of the healthcare practitioner's office are likely to affect their perceptions and responses in care settings.

Finding 2-1: Racial and ethnic disparities in healthcare occur in the context of broader historic and contemporary social and economic inequality, and evidence of persistent racial and ethnic discrimination in many sectors of American life.

ASSESSING POTENTIAL SOURCES OF DISPARITIES IN CARE

The studies cited above suggest that a range of patient-level, provider-level, and system-level factors may be involved in racial and ethnic healthcare disparities, beyond access-related factors.

Patient-Level Variables: The Role of Preferences, Treatment Refusal and the Clinical Appropriateness of Care

Racial and ethnic disparities in care may emerge, at least in part, from a number of patient-level attributes. For example, minority patients are more likely to refuse recommended services (e.g., Sedlis et al., 1997), adhere poorly to treatment regimens, and delay seeking care

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(e.g., Mitchell and McCormack, 1997). These behaviors and attitudes can develop as a result of a poor cultural match between minority patients and their providers, mistrust, misunderstanding of provider instructions, poor prior interactions with healthcare systems, or simply from a lack of knowledge of how to best use healthcare services. However, racial and ethnic differences in patient preferences and care-seeking behaviors and attitudes are unlikely to be major sources of healthcare disparities. For example, while minority patients have been found to refuse recommended treatment more often than whites, differences in refusal rates are small and have not fully accounted for racial and ethnic disparities in receipt of treatments (Hannan et al., 1999; Ayanian et al., 1999). Overuse of some clinical services (i.e., use of services when not clinically indicated) may be more common among white than minority patients, and may contribute to racial and ethnic differences in discretionary procedures. Several recent studies, however, have assessed racial differences relative to established criteria (Hannan et al., 1999; Laouri et al., 1997; Canto et al., 2000; Peterson et al., 1997) or objective diagnostic information, and still find racial differences in receipt of care. Other studies find that overuse of cardiovascular services among whites does not explain racial differences in service use (Schneider et al., 2001).

Finally, some researchers have speculated that biologically based racial differences in clinical presentation or response to treatment may justify racial differences in the type and intensity of care provided. For example, racial and ethnic group differences are found in response to drug therapies such as enalapril, an angiotensin-converting–enzyme inhibitor used to reduce the risk of heart failure (Exner et al., 2001). These differences in response to drug therapy, however, are not due to "race" *per se* but can be traced to differences in the distribution of polymorphic traits between population groups (Wood, 2001), and are small in relation to the common benefits of most therapeutic interventions. Further, as noted above, the majority of studies document disparities in healthcare services and disease areas when interventions are equally effective across population groups – making the "racial differences" hypothesis an unlikely explanation for observed disparities in care.

Finding 4-2: A small number of studies suggest that racial and ethnic minority patients are more likely than white patients to refuse treatment. These studies find that differences in refusal rates are generally small and that minority patient refusal does not fully explain healthcare disparities.

Healthcare Systems-Level Factors

Aspects of health systems – such as the ways in which systems are organized and financed, and the availability of services – may exert different effects on patient care, particularly for racial and ethnic minorities. Language barriers, for example, pose a problem for many patients where health systems lack the resources, knowledge, or institutional priority to provide interpretation and translation services. Nearly 14 million Americans are not proficient in English, and as many as one in five Spanish-speaking Latinos reports not seeking medical care due to language barriers (The Robert Wood Johnson Foundation, 2001). Similarly, time pressures on physicians may hamper their ability to accurately assess presenting symptoms of minority patients, especially where cultural or linguistic barriers are present. Further, the geographic availability of healthcare institutions – while largely influenced by economic factors that are outside the charge of this study – may have a differential impact on racial and ethnic minorities, independent of insurance status (Kahn et al., 1994). A study of the availability of opioid supplies, for

example, revealed that only one in four pharmacies located in predominantly non-white neighborhoods carried adequate supplies, compared with 72% of pharmacies in predominantly white neighborhoods (Morrison et al., 2000). Perhaps more significantly, changes in the financing and delivery of healthcare services – such as the shifts brought by cost-control efforts and the movement to managed care – may pose greater barriers to care for racial and ethnic minorities than for non-minorities (Rice, this volume). Increasing efforts by states to enroll Medicaid patients in managed care systems, for example, may disrupt traditional community-based care and displace providers who are familiar with the language, culture, and values of ethnic minority communities (Leigh, Lillie-Blanton, Martinez, and Collins, 1999). In addition, research indicates that minorities enrolled in publicly funded managed care plans are less likely to access services after mandatory enrollment in an HMO, compared with whites and other minorities enrolled in non-managed care plans (Tai-Seale et al, 2000).

Care Process-Level Variables: The Role of Bias, Stereotyping, Uncertainty

Three mechanisms might be operative in healthcare disparities from the provider's side of the exchange: bias (or prejudice) against minorities; greater clinical uncertainty when interacting with minority patients; and beliefs (or stereotypes) held by the provider about the behavior or health of minorities (Balsa and McGuire, 2001). Patients might also react to providers' behavior associated with these practices in a way that also contributes to disparities. Unfortunately, little research has been conducted to elucidate how patient race or ethnicity may influence physician decision-making and how these influences affect the quality of care provided. In the absence of such research, the study committee drew upon a mix of theory and relevant research to understand how clinical uncertainty, biases or stereotypes, and prejudice might operate in the clinical encounter.

Clinical Uncertainty

Any degree of uncertainty a physician may have relative to the condition of a patient can contribute to disparities in treatment. Doctors must depend on inferences about severity based on what they can see about the illness and on what else they observe about the patient (e.g., race). The doctor can therefore be viewed as operating with prior beliefs about the likelihood of patients' conditions, "priors" that will be different according to age, gender, socioeconomic status, and race or ethnicity. When these priors – which are taught as a cognitive heuristic to medical students – are considered alongside the information gained in a clinical encounter, both influence medical decisions.

Doctors must balance new information gained from the patient (sometimes with varying levels of accuracy) and their prior expectations about the patient to determine the diagnosis and course of treatment. If the physician has difficulty accurately understanding the symptoms or is less sure of the "signal" – the set of clues and indications that physicians rely upon to make diagnostic decisions – then he or she is likely to place greater weight on the "priors." The consequence is that treatment decisions and patients' needs are potentially less well matched.

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The Implicit Nature of Stereotypes

A large body of research in psychology has explored how stereotypes evolve, persist, shape expectations, and affect interpersonal interactions. Stereotyping can be defined as the process by which people use social categories (e.g., race, sex) in acquiring, processing, and recalling information about others. The beliefs (stereotypes) and general orientations (attitudes) that people bring to their interactions help to organize and simplify complex or uncertain situations and give perceivers greater confidence in their ability to understand a situation and respond in efficient and effective ways (Mackie, Hamilton, Susskind, & Rosselli, 1996).

Although functional, social stereotypes and attitudes also tend to be systematically biased. These biases may exist in overt, explicit forms, as represented by traditional bigotry. However, because their origins arise from virtually universal social categorization processes, they may also exist, often unconsciously, among people who strongly endorse egalitarian principles and truly believe that they are not prejudiced (Dovidio & Gaertner, 1998). In the United States, because of shared socialization influences, there is considerable empirical evidence that even well-meaning whites who are not overtly biased and who do not believe that they are prejudiced typically demonstrate unconscious implicit negative racial attitudes and stereotypes (Dovidio, Brigham, Johnson, & Gaertner, 1996). Both implicit and explicit stereotypes significantly shape interpersonal interactions, influencing how information is recalled and guiding expectations and inferences in systematic ways. They can also produce self-fulfilling prophecies in social interaction, in that the stereotypes of the perceiver influence the interaction with others in ways that conform to stereotypical expectations (Jussim, 1991).

Healthcare Provider Prejudice or Bias

Prejudice is defined in psychology as an unjustified negative attitude based on a person's group membership (Dovidio et al., 1996). Survey research suggests that among white Americans, prejudicial attitudes toward minorities remain more common than not, as over half to three-quarters believe that relative to whites, minorities – particularly African Americans – are less intelligent, more prone to violence, and prefer to live off of welfare (Bobo, 2001). It is reasonable to assume, however, that the vast majority of healthcare providers find prejudice morally abhorrent and at odds with their professional values. But healthcare providers, like other members of society, may not recognize manifestations of prejudice in their own behavior.

While there is no direct evidence that provider biases affect the quality of care for minority patients, research suggests that healthcare providers' diagnostic and treatment decisions, as well as their feelings about patients, are influenced by patients' race or ethnicity. Schulman et al. (1999), for example, found that physicians referred white male, black male, and white female hypothetical "patients" (actually videotaped actors who displayed the same symptoms of cardiac disease) for cardiac catheterization at the same rates (approximately 90% for each group), but were significantly less likely to recommend catheterization procedures for black female patients exhibiting the same symptoms. Weisse et al (2001), using a similar methodology as that of Schulman, found that male physicians prescribed twice the level of analgesic medication for white "patients" than for black "patients." Female physicians, in contrast, prescribed higher doses of analgesics for black than for white "patients," suggesting that male and female physicians may respond differently to gender and/or racial cues. In another experimental design, Abreu (1999) found that mental health professionals subliminally "primed" with African American stereotype-laden words were more likely to evaluate the same hypothetical patient (whose

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race was not identified) more negatively than when primed with neutral words. And in a study based on actual clinical encounters, van Ryn and Burke (2000) found that doctors rated black patients as less intelligent, less educated, more likely to abuse drugs and alcohol, more likely to fail to comply with medical advice, more likely to lack social support, and less likely to participate in cardiac rehabilitation than white patients, even after patients' income, education, and personality characteristics were taken into account. These findings suggest that while the relationship between race or ethnicity and treatment decisions is complex and may also be influenced by gender, providers' perceptions and attitudes toward patients are influenced by patient race or ethnicity, often in subtle ways.

Medical Decisions Under Time Pressure with Limited Information

Studies suggest that several characteristics of the clinical encounter increase the likelihood that stereotypes, prejudice, or uncertainly may influence the quality of care for minorities (van Ryn, 2002). In the process of care, health professionals must come to judgments about patients' conditions and make decisions about treatment, often without complete and accurate information. In most cases, they must do so under severe time pressure and resource constraints. The assembly and use of these data are affected by many influences, including various "gestalts" or cognitive shortcuts. In fact, physicians are commonly trained to rely on clusters of information that functionally resemble the application of "prototypic" or stereotypic constellations. These conditions of time pressure, resource constraints, and the need to rely on gestalts map closely onto those factors identified by social psychologists as likely to produce negative outcomes due to lack of information, to stereotypes, and to biases (van Ryn, 2002).

Patient Response: Mistrust and Refusal

As noted above, the responses of racial and ethnic minority patients to healthcare providers are also a potential source of disparities. Little research has been conducted as to how patients may influence the clinical encounter. It is reasonable to speculate, however, that if patients convey mistrust, refuse treatment, or comply poorly with treatment, providers may become less engaged in the treatment process, and patients are less likely to be provided with more vigorous treatments and services. But these kinds of reactions from minority patients may be understandable as a response to negative racial experiences in other contexts, or to real or perceived mistreatment by providers. Survey research, for example, indicates that minority patients perceive higher levels of racial discrimination in healthcare than non-minorities (LaVeist, Nickerson, and Bowie, 2000; Lillie-Blanton et al., 2000). Patients' and providers' behavior and attitudes may therefore influence each other reciprocally, but reflect the attitudes, expectations, and perceptions that each has developed in a context where race and ethnicity are often more salient than these participants are even aware of. In addition, it is clear that the healthcare provider, rather than the patient, is the more powerful actor in clinical encounters. Providers' expectations, beliefs, attitudes, and behaviors are therefore likely to be a more important target for intervention efforts.

Finding 3-1: Many sources – including health systems, healthcare providers, patients, and utilization managers – may contribute to racial and ethnic disparities in healthcare.

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Finding 4-1: Bias, stereotyping, prejudice, and clinical uncertainty on the part of healthcare providers may contribute to racial and ethnic disparities in healthcare. While indirect evidence from several lines of research supports this statement, a greater understanding of the prevalence and influence of these processes is needed and should be sought through research.

INTERVENTIONS TO ELIMINATE RACIAL AND ETHNIC DISPARITIES IN HEALTHCARE

Legal, Regulatory and Policy Interventions

"De-Fragmentation" of Healthcare Financing and Delivery

Racial and ethnic minorities are more likely than whites to be enrolled in "lower-end" health plans, which are characterized by higher per capita resource constraints and stricter limits on covered services (Phillips et al., 2000). The disproportionate presence of racial and ethnic minorities in lower-end health plans is a potential source of healthcare disparities, given that efforts to control for insurance status in studies of healthcare disparities have not taken detailed account of variations among health plans. Such socioeconomic fragmentation of health plans engenders different clinical cultures, with different practice norms, tied to varying per capita resource constraints (Bloche, 2001).

Equalizing access to high-quality plans can limit such fragmentation. Public healthcare payors such as Medicaid should strive to help beneficiaries access the same health products as privately-insured patients. This recommendation is also reflected in the IOM *Quality Chasm* report's strategies for focusing health systems on quality, in its call to "eliminate or modify payment practices that fragment the care system" (IOM, 2001, p. 13).

Recommendation 5-1: Avoid fragmentation of health plans along socioeconomic lines.

Strengthening Doctor-Patient Relationships

Several lines of research suggest that the consistency and stability of the doctor-patient relationship is an important determinant of patient satisfaction and access to care. Having a usual source of care is associated, for example, with use of preventive care services (Agency for Healthcare Research and Quality, 2001). In addition, having a consistent relationship with a primary care provider may help to address minority patient mistrust of healthcare systems and providers, particularly if the relationship is with a provider who is able to bridge cultural and linguistic gaps (LaViest, Nickerson, and Bowie, 2000). Minority patients, however, are less likely to enjoy a consistent relationship with a provider, even when insured at the same levels as white patients (Lillie-Blanton, Martinez, and Salganicoff, 2001). This is due in part to the types of health systems in which they are enrolled and the relative lack of providers located in minority communities.

Health systems should attempt to ensure that every patient, whether insured privately or publicly, has a sustained relationship with an attending physician able to help the patient effectively navigate the healthcare bureaucracy. Federal and state performance standards for Medicaid managed care plans, for example, should include guidelines to ensure the stability of pa-

tients' assignments to primary care providers (and these providers' accessibility), reasonable patient loads per primary care physician, and time allotments for patient visits.

Recommendation 5-2: Strengthen the stability of patient-provider relationships in publicly-funded health plans.

Patient and provider relationships will also be strengthened by greater racial and ethnic diversity in the health professions. Racial concordance of patient and provider is associated with greater patient participation in care processes, higher patient satisfaction, and greater adherence to treatment (Cooper-Patrick et al., 1999). In addition, racial and ethnic minority providers are more likely than their non-minority colleagues to serve in minority and medically underserved communities (Komaromy et al., 1996). The benefits of diversity in health professions fields are significant, and illustrate that a continued commitment to affirmative action is necessary for graduate health professions education programs, residency recruitment, and other professional opportunities.

Recommendation 5-3: Increase the proportion of underrepresented U.S. racial and ethnic minorities among health professionals.

Patient Protections

Much of the political focus on Capitol Hill in the summer of 2001 was devoted to managed care regulation. To one extent or another, the various bills debated would all extend protections to enrollees in private managed care organizations, providing avenues for appeal of care denial decisions, improving access to specialty care, requiring health plans to disclose information about coverage, banning physician "gag" clauses, and providing other legal remedies to resolve disputes. Publicly funded health plans, however, are not addressed in these legislative proposals. Given that many minorities are disproportionately represented among the publicly insured who receive care within managed care organizations, the same patient protections that apply to the privately insured should apply to those in publicly funded plans (Hashimoto, 2001).

Recommendation 5-4: Apply the same managed care protections to publicly funded HMO enrollees that apply to private HMO enrollees.

Civil Rights Enforcement

Enforcement of regulation and statute is also an important component of a comprehensive strategy to address healthcare disparities, but unfortunately has been too often relegated to low-priority status. The U.S. DHHS Office of Civil Rights (OCR) is charged with enforcing several relevant federal statutes and regulations that prohibit discrimination in healthcare (principally Title VI of the 1964 Civil Rights Act). The agency, however, has suffered from insufficient resources to investigate complaints of possible violations, and has long abandoned proactive, investigative strategies (Smith, 1999). Complaints to the agency declined in the early 1990s, but have increased in recent years, while funding has remained level in terms of appropriated dollars but lower in terms of spending power after adjusting for inflation (U.S. Commission on Civil

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Rights, 2001). The agency should be equipped with sufficient resources to better address these complaints and carry out its oversight responsibilities.

Recommendation 5-5: Provide greater resources to the U.S. DHHS Office of Civil Rights to enforce civil rights laws.

Health Systems Interventions

A variety of interventions applied at the level of health systems may be effective as a part of a comprehensive, multi-level strategy to address racial and ethnic disparities in healthcare.

Evidence-Based Cost Control

In the current era of continually escalating healthcare costs, cost containment is an important goal of all health systems. To the extent possible, however, medical limit setting by health plans should be based on evidence of effectiveness. The application of evidence to healthcare delivery, such as through the use of evidence-based guidelines, can help to address the problem of potential underuse of services resulting from capitation or per case payment methods, as noted in the IOM *Quality Chasm* report (IOM, 2001). Evidence-based guidelines offer the advantages of consistency, predictability, and objectivity that general, discretionary advisory statements do not. In addition, because evidence-based guidelines and standards directly promote accountability, they also indirectly affect equity of care.

In actual practice, however, a pragmatic balance must be sought between the advantages and limitations of guidelines, such as the tension between the goal of standardization versus the need for clinical flexibility. Disclosing health plans' clinical protocols offers one means of achieving this balance, as it would aid both private sector and public efforts in balancing the virtues of rules and discretion. To achieve this, private accrediting entities and state regulatory bodies could require that health plans publish their clinical practice protocols, along with supporting evidence, thereby opening these protocols to professional and consumer review (Bloche, 2001).

Recommendation 5-6: Promote the consistency and equity of care through the use of evidence-based guidelines.

Financial Incentives in Healthcare

Financial factors, such as capitation and health plan incentives to providers to practice frugally, can pose greater barriers to racial and ethnic minority patients than to white patients, even among patients insured at the same level. Low payment rates limit the supply of physician (and other healthcare provider) services to low-income groups, disproportionately affecting ethnic minorities (Rice, this volume). Inadequate supply takes the form of too few providers participating in plans serving the poor, and provider unwillingness to spend adequate time with patients. This time pressure may contribute to poor information exchange between physicians and members of minority groups.

If appropriately crafted, however, financial incentives to physicians can serve a positive role in efforts to reduce disparities in care. Economic rewards for time spent engaging patients

and their families can help physicians to overcome barriers of culture, communication, and empathy. In addition, incentives that encourage physicians to adhere to evidence-based protocols for frugal practice and to engage in age- and gender-appropriate disease screening can promote efficient, quality care and penalize deviations, regardless of race or ethnicity. Further, financial incentives linked to favorable clinical outcomes, where reasonably measurable (e.g. control of diabetes, asthma, and high blood pressure) can also promote equity of care (Bloche, 2001). Again, this recommendation is consistent with the IOM *Quality Chasm* report, which calls for healthcare organizations, clinicians, purchasers, and other stakeholders to "align the incentives inherent in payment and accountability processes with the goal of quality improvement" (IOM, 2001, p.10).

Recommendation 5-7: Structure payment systems to ensure an adequate supply of services to minority patients and limit provider incentives that may promote disparities.

Recommendation 5-8: Enhance patient-provider communication and trust by providing financial incentives for practices that reduce barriers and encourage evidence-based practice.

Interpretation Services

As noted above, many racial and ethnic minorities find that language barriers pose a significant problem in their efforts to access healthcare. Language barriers may affect the delivery of adequate care through poor exchange of information, loss of important cultural information, misunderstanding of physician instruction, poor shared decision making, or ethical compromises (e.g., difficulty obtaining informed consent; Woloshin et al., 1995). Linguistic difficulties may also result in decreased adherence with medication regimes, poor appointment attendance (Manson, 1988), and decreased satisfaction with services (Carrasquillo et al., 1999; David and Rhee, 1998; Derose & Baker, 2000).

Broader use of professional interpretation services has been hampered by a number of logistical and resource constraints. For example, in some regions of the country, few trained professional interpreters are available, and reimbursement for interpretation services via publicly funded insurance such as Medicaid is often inadequate. Greater resources are needed to support professional interpretation services, and more research and innovation should identify effective means to harness new technologies (e.g., simultaneous telephone interpretation) to aid interpretation.

Recommendation 5-9: Support the use of interpretation services where community need exists.

Community Health Workers

Community health workers – often termed lay health advisors, neighborhood workers, indigenous health workers, health aides, *consejera*, or *promotora* – fulfill multiple functions in helping to improve access to healthcare. Community health workers can serve as liaisons between patients and providers, educate providers about community needs and the culture of the community, provide patient education, contribute to continuity and coordination of care, assist in

appointment attendance and adherence to medication regimens, and help to increase the use of preventive and primary care services (Brownstein et al., 1992, Earp & Flax, 1999; Jackson & Parks, 1997). In addition, some evidence suggests that lay health workers can help improve the quality of care and reduce costs (Witmer et al., 1995), and improve general wellness by facilitating community access to and negotiation for services (Rodney et al., 1998).

Recommendation 5-10: Support the use of community health workers.

Multidisciplinary Teams

Research demonstrates that multidisciplinary team approaches – including physicians, nurses, dietitians, and social workers, among others – can effectively optimize patient care. This effect is found in randomized controlled studies of patients with coronary heart disease, hypertension, and other diseases, and has extended to strategies for reducing risk behaviors and conditions such as smoking, sedentary lifestyle and obesity (Hill and Miller, 1996). Multidisciplinary teams coordinate and streamline care, enhance patient adherence through follow-up techniques, and address the multiple behavioral and social risks faced by patients. These teams may save costs and improve the efficiency of care by reducing the need for face-to-face physician visits and improve patients' day-to-day care between visits. Further, such strategies have proven effective in improving health outcomes of minorities previously viewed as "difficult to serve" (Hill and Miller, 1996). Multidisciplinary team approaches should be more widely instituted as strategy for improving care delivery, implementing secondary prevention strategies, and enhancing risk reduction.

Recommendation 5-11: Implement multidisciplinary treatment and preventive care teams.

Patient Education and Empowerment

Increasingly, researchers are recognizing the important role of patients as active participants in clinical encounters (Korsch, 1984). Patient education efforts have taken many forms, including the use of books and pamphlets, in-person instruction, CD-ROM-based educational materials, and internet-based information. These materials guide patients through typical office visits and provide information about asking appropriate questions and having their questions answered, communicating with the provider when instructions are not understood or cannot be followed, and being an active participant in decision-making. While evaluation data are limited, particularly with respect to racial and ethnic minority patients, preliminary evidence suggests that patient education can improve patients' skills and knowledge of clinical encounters and improve their participation in care decisions.

Recommendation 5-12: Implement patient education programs to increase patients' knowledge of how to best access care and participate in treatment decisions.

Cross-Cultural Education in the Health Professions

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Given the increasing racial and ethnic diversity of the U.S. population, the development and implementation of training programs for healthcare providers offers promise as a key intervention strategy in reducing healthcare disparities. As a result, cross-cultural education programs have been developed to enhance health professionals' awareness of how cultural and social factors influence healthcare, while providing methods to obtain, negotiate and manage this information clinically once it is obtained. Cross-cultural education can be divided into three conceptual approaches focusing on *attitudes* (cultural sensitivity/awareness approach), *knowledge* (multicultural/categorical approach), and *skills* (cross-cultural approach), and has been taught using a variety of interactive and experiential methodologies. Research to date demonstrates that training is effective in improving provider knowledge of cultural and behavioral aspects of healthcare and building effective communication strategies. Despite progress in the field, however, several challenges exist, including the need to define educational core competencies, reach consensus on approaches and methodologies, determine methods of integration into the medical and nursing curriculum, and develop and implement appropriate evaluation strategies. These challenges should be addressed to realize the potential of cross-cultural education strategies.

Recommendation 6-1: Integrate cross-cultural education into the training of all current and future health professionals.

DATA COLLECTION AND MONITORING

Standardized data collection is critically important in the effort to understand and eliminate racial and ethnic disparities in healthcare. Data on patient and provider race and ethnicity would allow researchers to better disentangle factors that are associated with healthcare disparities, help health plans to monitor performance, ensure accountability to enrolled members and payors, improve patient choice, allow for evaluation of intervention programs, and help identify discriminatory practices. Unfortunately, standardized data on racial and ethnic differences in care are generally unavailable. Federal and state-supported data collection efforts are scattered and unsystematic, and many health plans, with a few notable exceptions, do not collect data on enrollees' race, ethnicity, or primary language.

A number of ethical, logistical, and fiscal concerns present challenges to data collection and monitoring, including the need to protect patient privacy, the costs of data collection, and resistance from healthcare providers, institutions, plans and patients. In addition, health plans have raised significant concerns about how such data will be analyzed and reported. The challenges to data collection should be addressed, as the costs of failing to assess racial and ethnic disparities in care may outweigh new burdens imposed by data collection and analysis efforts.

Recommendation 7-1: Collect and report data on healthcare access and utilization by patients' race, ethnicity, socioeconomic status, and where possible, primary language.

Recommendation 7-2: Include measures of racial and ethnic disparities in performance measurement.

Recommendation 7-3: Monitor progress toward the elimination of healthcare disparities.

Recommendation 7-4: Report racial and ethnic data by federally-defined categories, but use subpopulation groups where possible.

NEEDED RESEARCH

While the literature that the committee reviewed provides significant evidence of racial and ethnic disparities in care, the evidence base from which to better understand and eliminate disparities in care remains less than clear. Several broad areas of research are needed to clarify how race and ethnicity are associated with disparities in the process, structure, and outcomes of care. Research must provide a better understanding of the contribution of patient, provider, and institutional characteristics on the quality of care for minorities. Research has been notably absent in other areas. More research is needed, for example, to understand the extent of disparities in care faced by Asian-American, Pacific-Islander, American Indian and Alaska Native, and Hispanic populations, and to better understand and surmount barriers to research on healthcare disparities, including those related to ethical issues in data collection.

Recommendation 8-1: Conduct further research to identify sources of racial and ethnic disparities and assess promising intervention strategies.

Recommendation 8-2: Conduct research on ethical issues and other barriers to eliminating disparities.

Summary of Findings

Finding 1-1: Racial and ethnic disparities in healthcare exist and, because they are associated with worse outcomes in many cases, are unacceptable.
Finding 2-1: Racial and ethnic disparities in healthcare occur in the context of broader historic and contemporary social and economic inequality, and evidence of persistent racial and ethnic discrimination in many sectors of American life.
Finding 3-1: Many sources – including health systems, healthcare providers, patients, and utilization managers – may contribute to racial and ethnic disparities in healthcare.
Finding 4-1: Bias, stereotyping, prejudice, and clinical uncertainty on the part of healthcare providers may contribute to racial and ethnic disparities in healthcare. While indirect evidence from several lines of research supports this statement, a greater understanding of the prevalence and influence of these processes is needed and should be sought through research.
Finding 4-2: A small number of studies suggest that racial and ethnic minority patients are more likely than white patients to refuse treatment. These studies find that differences in refusal rates are generally small and that minority patient refusal does not fully explain healthcare disparities.

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Summary of Recommendations

General Recommendations
Increase awareness of racial and ethnic disparities in healthcare among the general public and key stakeholders (Recommendation 2-1).
Increase healthcare providers' awareness of disparities (Recommendation 2-2).

Legal, Regulatory, and Policy Interventions
Avoid fragmentation of health plans along socioeconomic lines (Recommendation 5-1).
Strengthen the stability of patient-provider relationships in publicly funded health plans (Recommendation 5-2).
Increase the proportion of underrepresented U.S. racial and ethnic minorities among health professionals (Recommendation 5-3).
Apply the same managed care protections to publicly funded HMO enrollees that apply to private HMO enrollees (Recommendation 5-4).
Provide greater resources to the U.S. DHHS Office of Civil Rights to enforce civil rights laws (Recommendation 5-5).

Health Systems Interventions
Promote the consistency and equity of care through the use of evidence-based guidelines (Recommendation 5-6).
Structure payment systems to ensure an adequate supply of services to minority patients, and limit provider incentives that may promote disparities (Recommendation 5-7).
Enhance patient-provide communication and trust by providing financial incentives for practices that reduce barriers and encourage evidence-based practice (Recommendation 5-8).
Support the use of interpretation services where community need exists (Recommendation 5-9).
Support the use of community health workers (Recommendation 5-10).
Implement multidisciplinary treatment and preventive care teams (Recommendation 5-11).

Patient Education and Empowerment
Implement patient education programs to increase patients' knowledge of how to best access care and participate in treatment decisions (Recommendation 5-12).

Cross-Cultural Education in the Health Professions
Integrate cross-cultural education into the training of all current and future health professionals (Recommendation 6-1).

Data Collection and Monitoring
Collect and report data on health care access and utilization by patients' race, ethnicity, socioeconomic status, and where possible, primary language (Recommendation 7-1).
Include measures of racial and ethnic disparities in performance measurement (Recommendation 7-2).
Monitor progress toward the elimination of healthcare disparities (Recommendation 7-3).
Report racial and ethnic data by OMB categories, but use subpopulation groups where possible (Recommendation 7-4).

Research Needs
Conduct further research to identify sources of racial and ethnic disparities and assess promising intervention strategies (Recommendation 8-1).
Conduct research on ethical issues and other barriers to eliminating disparities (Recommendation 8-2).

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Prejudice, Clinical Uncertainty and Stereotyping as Sources of Health Disparities[1]

Ana I. Balsa
Department of Economics
Boston University

Thomas G. McGuire
Department of Health Care Policy
Harvard Medical School

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Abstract

Disparities in health can result from the clinical encounter between a doctor and a patient. This paper identifies and studies three possible mechanisms: prejudice of doctors in the form of being less willing to interact with members of minority groups, increased clinical uncertainty associated with doctors' interpretation of symptoms from minority patients, and stereotypes doctors hold about health-related behavior of minority patients, such as their willingness to comply with treatment. Within a unified conceptual framework, we show how all three can lead to disparities in health and health services use of members of minority groups. We then go on to study how social policy might reduce disparities stemming from each cause. We consider policies to improve the accuracy of information doctors have about members of minority groups and policies that mandate the doctor to act on the basis of a particular rule ("rule-based" treatment). The effect of social policy depends critically on the underlying cause of disparities. One finding is that when information is the cause, but "rule-based" treatment is the policy action, health outcomes can be degraded for all social groups. Policy to reduce disparities should be based on evidence about the nature of the cause of disparities.

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1 Introduction

A health care disparity exists when membership in a social group (race or gender, for example) influences health care treatment or outcomes in a way that is unjustified by the underlying need of the patient. Considerable empirical research has documented widespread disparities in health and in use of health services among racial/ethnic groups in the U.S. A striking development in health policy in the U.S. in the past few years has been the rapid emergence of a consensus that reducing disparities should be a major goal of public health and social policy.

Some disparities in health and health services can be attributed to "social factors" such as the higher likelihood of being uninsured for Blacks and Latinos (Monheit and Vistnes, 2000), transportation in inner cities (Heckman et al., 1998) or over representation of minorities in Medicaid health plans with restrictive payment policies (TaiSeale, Freund and LoSasso, 2001). Empirical research has found disparities, however, even when these social factors are ruled out by controls or by design. In some "experiments" in which insurance, access, and other factors do not vary, black patients are treated differently than white patients.[2] In other words, disparities may arise from

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[2] The literature documenting disparities is voluminous. The following is a quote from an excellent recent review of the literature on the added "risk" of being Black after controlling for insurance and socioeconomic status (Fiscella, K., Franks, P., Gold, M.R, and Clancey, C.M, 2000). We omit the 24 references cited by the authors:

"Elderly Blacks, compared with Whites, are seen less often by specialists, receive less appropriate preventive care including mammography and influenza vaccinations, lower quality hospital care, and fewer expensive, technological procedures. In general, Blacks receive less intensive hospital care, including fewer cardiovascular procedures, lung resec-

the interaction between doctor and patient. In this paper, we are concerned with disparities from this second source, the clinical encounter. In particular, we focus on disparities that originate in the physician's behavior, including any demand-side reaction to that behavior.[3]

One view of the origin of these disparities is that health care providers are simply prejudiced against members of minority groups and treat these patients with lower regard than Whites. Another commonly mentioned hypothesis is that providers hold preconceptions about patients that are conditioned on group membership. Doctors' "stereotypes" that minority patients are less likely to comply with treatment, for example, might generate disparities. Finally, in an earlier paper, we show how the presence of greater uncertainty in interpreting symptoms of disease for minority patients can itself be a source of disparate treatment, even among fair-minded providers (Balsa and McGuire, forthcoming). All three of these explanations are a form of what social psychologists label "group categorization," that is, acting toward a person based in part on their membership in a social group like race or ethnicity.

In the sections that follow, we study doctors' group-based decisions of the

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tions for cancer, kidney and bone marrow transplants, cesarean sections, peripheral vascular procedures, and orthopedic procedures. They have also been reported to receive less aggressive treatment of prostate cancer, fewer antiretrovirals for human immunodeficiency virus infection, antidepressants for depression, tympanostomy tubes, and admissions for chest pain, and lower-quality prenatal care."

The next paragraphs in the article discuss evidence (less extensive) for Latinos and Asians.

[3] Some physician-side explanations, such as stereotypic beliefs, have parallels on the patient side. A complete study of the sources of clinical disparities should include attention to these patient-side explanations.

following form: being less willing to interact with members of the minority group (prejudice), interpreting a symptom of illness as a less reliable indicator of severity for a minority patient or holding differential beliefs about the group's underlying severity (clinical uncertainty)[4], and holding a belief that minority patients are less likely to comply with treatment recommendations (stereotyping). In conducting this analysis we rely heavily on the labor economics literature - the field of economics where issues related to discrimination have been treated most extensively.[5]

Within a unified framework, we link our analysis to policy and show that policies to address disparities will work differently depending on which mechanism is responsible. We consider information-based policies to reduce uncertainty or to break stereotypical patterns. We also consider enforcing "rule-based" policies that require, for example, that Blacks be treated the same as Whites. All policies have costs of implementation, of course, but in our discussion of policies, we focus on the potential benefits of information and rule-based approaches. Information-based policies, though ineffective when information is not the underlying problem, at least satisfy the medical creed, "first, do no harm." Rule-based policies run a greater risk of unintended consequences. Enforcing parity in treatment across racial groups without dealing with information problems that might be generating the disparities in the first place can degrade the value of health care for all so-

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[4] Our earlier paper, Balsa and McGuire (forthcoming) analyzed the implications of greater uncertainty in doctor's interpretation of symptom-signals from the minority patients. In the current paper we extend this analysis to show how even when the degree of uncertainty is the same for different patient groups, differences in doctors' prior beliefs (even if accurate), can lead to disparities in treatment.

[5] We have drawn most heavily from Becker (1971), Arrow(1973), Lundberg and Startz (1983) and Coate and Loury(1993).

cial groups – a lose-lose proposition. One conclusion of our analysis is that social policy to reduce disparities arising from the clinical encounter should be based on evidence that differentiates among the possible routes of cause.

Before we analyze disparities stemming from the clinical encounter, we first define a standard or benchmark of clinical decision-making that is both fair and efficient.

2 The Benchmark: A Benevolent Doctor with Complete Information

In this section we introduce a simple model of illness and treatment to define standards of fairness and efficiency. In later sections, we build on the model to study the role of racial or ethnic group based decisions in disparities. Our analysis will be conducted using two racial groups, but it applies to ethnic as well as racially defined minorities.

Patients are members of one of two recognizable groups, Blacks and Whites, which we will refer to as race. Race is the potential basis of categorization by doctors. Each patient is also characterized by a severity of illness, denoted Z. A patient with a higher value of Z is more severely ill. Blacks and Whites may differ in the underlying distribution of severity. For Blacks, $Z \sim N(\mu_B, \sigma^2)$, and for Whites, $Z \sim N(\mu_W, \sigma^2)$. That is, the distribution of severity may have a different mean for Blacks and Whites (if $\mu_B < \mu_W$, Blacks are "healthier" on average, if $\mu_B > \mu_W$, the opposite is true). We assume here that the variance in the distribution of severity is the same for both groups.

Treatment is a simple yes/no decision made by the doctor. If a patient of severity Z is treated, he or she receives benefits $B = Z$. We interpret

a negative value of Z as meaning that the treatment is not effective from the doctor's point of view (either because the patient is not sick enough to justify the treatment or because the patient is healthy but bears some risk, a risk that might vary for different people). Z can be viewed as the net benefit a patient gets from treatment. For "healthy" patients, treatment only has risks but no benefits, so Z is negative. Given a value of Z, race does not matter in how a patient benefits from treatment. We assume for now that there are no costs of treatment (in a later section, doctors and patients will each face a cost).

We can now define what we mean by a fair and efficient allocation. An allocation consists of an assignment of patients to treatment or not by the doctor. An allocation is *fair* if, given severity, the treatment decision does not depend on group membership. In other words, a fair allocation means that for any Z, assignment of a patient to treatment or not does not depend on race. An allocation rule is *efficient* if there is no alternative rule that makes everyone at least as well off and some individuals strictly better off. With complete information an efficient rule leads to a "first best" allocation. In the context of imperfect information, a rule is efficient if, given the information available, there exists no alternative decision rule that can improve the outcome for some patients without decreasing the value of health care for others. We will call the "second best" efficient in a setting with imperfect information.

In the benchmark allocation the doctor is benevolent in the choice of treatment and has complete information about the patient's health needs. Race is always observable. The doctor is benevolent if, given the information available, the doctor makes his treatment recommendation so as to maximize the patient's expected benefits from treatment. (The doctor has no profit

or other personal motives.) Complete information refers to the doctor being able to accurately observe the severity Z of each patient. (The doctor is a perfect diagnostician.)

A benevolent doctor with complete information about severity assigns patients to treatment if and only if the benefits of treatment to the patient are positive. Figure 1 illustrates the benchmark case in which only patients with $Z \geq 0$ get treatment. The allocation is efficient because there is no way of changing the distribution of treatment without worsening the health-care outcomes of one or more patients. The allocation is fair because for any given severity, race doesn't matter in the doctor's decision about treatment. A Black or White with severity Z gets the same treatment assignment and outcome. Different numbers of Blacks and Whites may get treatment, but this does not constitute a disparity. Given need or severity, Blacks and Whites are treated the same. If $\mu_B < \mu_W$, for example, fewer Blacks will have values of $Z \geq 0$, and a smaller share of Blacks will be treated. This is purely due, however, to their lower average severity of illness (see Figure 1).

3 Prejudice

The most straightforward explanation for clinical disparities, and the one first proposed in the discrimination literature in labor economics, is that physicians hold a bias or a "prejudice" against members of other ethnic groups (Becker, 1971). "Prejudice" is a concept with a long history in social psychology. In a survey of this literature, Fiske (1998) defines prejudice as the affective component of category-based attitudes, distinct from cognitively based stereotypes and the behavior of discrimination.

According to the social psychology literature, prejudice stems from cer-

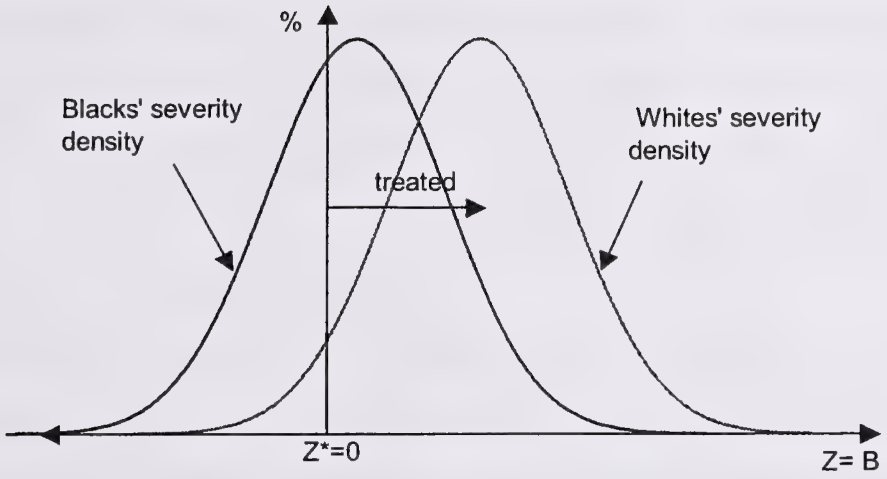

Figure 1: The Benevolent Doctor With Complete Information Treats Patients With a Positive Benefit

tain intergroup contexts (Fiske, 1998), such as group threats. Pettigrew and Meertens (1995) suggest that blatant prejudice comes partly from perceived threats to one's group, in terms of the group's relative position, jobs and welfare. Outgroup members are presumed to block ingroup goals, either by directly competing or by simply having different goals. Close personal contact is another force that can evoke prejudice, mainly due to the effort and personal threats conveyed in the intimacy with a person that seems different (familiarity smooths people's transactions, difference disrupts). Because interacting with an outgroup partner requires monitoring one's behavior, it may cause anxiety, discomfort and irritation, and eventually may result in prejudice. Also, interaction with an outgroup member may provoke hostility in an authoritarian person who feels his/her values are in question. All these explanations of prejudice share an underlying dimension of threat to the core of the prejudiced person. Whether these threats are real or just

perceived is another issue. A consistent finding of social identity research is that people tend to favor ingroup members in the distribution of rewards, even when these groups are arbitrarily categorized.[6] Even if an outgroup member conveys no real "threats" to the subject, the mere existence of a group is sufficient to wake in the subject feelings of familiarity (disruption) with ingroup (outgroup) members.

In economics, the concept of prejudice was first explored by Becker (1971) who defined it as a "taste" for discrimination and constructed a model of the labor market in which employers were prejudiced against members of the minority group. This distaste was represented as a (psychological) cost in the objective function of the prejudiced individual. A problem with Becker's approach to explaining labor market "disparities" is that they could not be sustained in the long run if there were competition from employers with diverse "tastes" for discrimination. In response to this criticism, one can argue that the health market is not as competitive as the labor market, and thus make a case for the possible persistence of taste discrimination in health care.[7] The health care market diverges from the competitive model mainly due to its barriers to the information flow between agents and its lack of insurance for a variety of risks (Arrow, 1963). Some of the health care market's characteristics that slow down the flow of information between buyers and sellers and promote non-competitive behavior are the non-verifiability of some medical services, the difficulties in evaluating quality, the asymmetry of information between physician and patient, the restrictions imposed to

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[6] The voting behavior of the "tribes" in the TV show "Survivor" is a visible social experiment.

[7] Almost all papers describing the doctor-patient market are based on a model of monopolistic competition in which the physician has some market power (McGuire, 2000).

entry to the medical profession, and the increasing returns to scale in some areas of care. Additionally, the market fails to provide insurance against all possible health care risks, such as the risk of failing to benefit from medical care. All these characteristics may shelter taste discrimination in the long run.

A second weakness of the traditional taste discrimination models is that they remain logically incomplete because they treat bigotry as a parameter in preferences, without endogenizing the behavior behind this prejudice (Arrow, 1998). A new strand in economics seeks to explain the appearance of these "transaction costs" between members of different groups by introducing concepts as choice of identity or differential learning (Akerlof and Kranton, 2000; Lundberg and Startz, 1998).[8] Although recognizing the forces behind prejudice may be necessary to contend with the fundamental problem (spanning health and other sectors), here, we follow Becker, and

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[8] Akerlof and Kranton (2000) construct a model in which individuals may suffer a loss of utility if their actions confront the prescriptions that define their identity or if others' actions confront these prescriptions (ingroups give the person a higher utility than outgroups). Persons choose both their identities and their actions to maximize the expected payoffs, given the probability of encounters with outgroup and ingroups members. Choice of identity and consequent actions may be a reaction to the dominant class rejection. Social interaction within the community and sense of rejection determine the prevalence of black identities. It does not really matter for the equilibrium whether the perceived problems reflect real problems between groups or those that are merely imagined because of the mismatch of ingroup and outgroup members' attitudes. Lundberg and Startz (1998) construct a framework in which agents search for partners to make transactions in an imperfect information setting. If agents believe that race defines meaningful groups and learning about signal-quality relationships is to some extent race specific, then small initial differences in the quality of information (including those due solely to group size) can lead to segregation and potentially, a self-reinforcing cycle of ignorance and avoidance.

assume that doctors bear an exogenous cost when interacting with minority group members.

3.1 Taste discrimination is unfair

We assume that non-competitive conditions in the market are sufficiently strong to sustain discriminatory forces in the long run. The white doctor experiences a psychological cost, or distaste, when dealing with a patient of a different race. We denote this cost as d. Assume $d = 0$ for white patients but $d > 0$ for black patients. As before, benefits from treatment are given by Z, but now the doctor maximizes the patient's benefit net of this psychological cost. Treatment is again a 0,1 decision and the doctor's strategy is to choose a threshold Z^* that determines the cut-off between patient who do and do not get treatment.

The obvious implication of this analysis is that Blacks will be undertreated. Figure 2 illustrates the most simple case, in which Blacks and Whites have the same distribution of severity. While all Whites with $Z \geq 0$ will be assigned to treatment, only Blacks with $Z \geq d$ will receive care. This allocation is unfair because for some severity levels, black patients are receiving a different treatment recommendation than White patients.

Whether the allocation is efficient or not depends on how we view the "psychological cost" experienced by the prejudiced doctors. If this cost is accepted as legitimate, it has to be taken into account when measuring society's total welfare. Then, the allocation resulting from taste discrimination is efficient because no other allocation can improve the situation of Black patients without having a detrimental effect on either White patients' health or on doctors' welfare. Alternatively, if "prejudice" is not accepted as a legit-

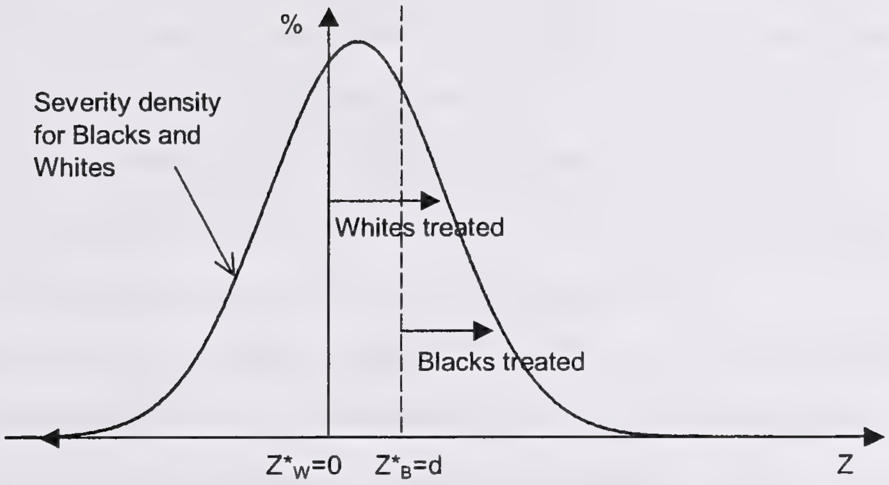

Figure 2: A Prejudiced Doctor Assigns Treatment to Blacks at a Lower Rate than Whites

imate preference or cost, the allocation resulting from taste discrimination is inefficient, since Black patients' situation can be improved by imposing a requirement upon doctors that they treat both races the same way.

4 Clinical uncertainty

We now set aside prejudice, and consider a second possible source of disparity in treatment. The doctor's decision making process is nested in uncertainty, a long-standing theme in health economics (Arrow, 1963; Eisenberg, 1986; Phelps, 2000). Upon encountering a patient, the doctor collects information in order to decide which is the likely cause of the problem and what actions to take to improve the patient's health. Doctors cannot observe disease and its severity, but can only observe signals, or symptoms, of the underlying problem. The doctor must depend on inferences about severity based on

what symptoms he can see and what else he observes about the patient (race, in our analysis). We assume that the doctor is Bayesian in his decision-making: after observing a signal, the doctor uses this signal to update his prior about the expectation of the patient's severity. The higher the doctor's uncertainty, the higher the weight placed by the doctor on the prior and the lower the weight placed on the signal or symptom.

Uncertainty by itself can generate disparities. In this section we show that despite the physician's benevolence, lack of complete information can result in an unfair outcome. In the first application, which we denote the "Miscommunication" model, a doctor may have more difficulty interpreting symptoms from Blacks than from Whites, perhaps because the doctor is White, and can communicate better with members of his own group (Cooper et al, 1999; Sue et al, 1991; Saha et al, 1999; Takeuchi et al, 1995). Phelps (1972) coined the term "statistical discrimination" to describe the labor market disparities that would result from an employer having a harder time assessing the productivities of black as compared to white workers. In an earlier paper (Balsa and McGuire, forthcoming) we applied some of these insights originating in labor economics to a health care context. In the second application, which we call the "Business Necessity" model, the doctor's ability to communicate with black patients is as good as his ability to communicate with white patients. However, the doctor believes that the underlying distribution of severity differs across races, and hence is willing to use the "category" race as an aid to improve his diagnosis when making an inference about the underlying severity of the patient. Both applications share a basic framework. As in the benchmark case, severity is normally distributed, $Z \sim N(\mu_i, \sigma^2)$, with $i \in \{B, W\}$. The difference here is that the doctor doesn't observe severity but only a signal of this severity which

we denote by S. $S = Z + \varepsilon$ where $\varepsilon \sim N(0, \sigma^2_{\varepsilon_i})$. The variance of the noise, $\sigma^2_{\varepsilon_i}$ is a measure of the degree of uncertainty present between the doctor and the patient and may also differ across races.

Doctors must make a decision about treatment based on the *expected benefits* of treatment. The benevolent (unprejudiced) doctor recommends treatment when the expected benefits of treatment are positive. The doctor uses Bayes' rule to update his priors given the signal he observes. For a patient with signal value S, the resulting expected benefit is equal to:

$$(1 - \beta_i)\mu_i + \beta_i S \qquad \textit{with} \;\; \beta_i = \frac{\sigma^2}{\sigma^2 + \sigma^2_{\varepsilon_i}} \tag{1}$$

Note that β_i is a measure of the quality of the signal. The noisier is the signal (the larger is $\sigma^2_{\varepsilon_i}$), the lower β_i, and the less weight the doctor puts on the signal itself relative to the severity mean, μ_i.

4.1 Miscommunication leads to disparities

We analyze the miscommunication hypothesis using a simple case. We assume that doctors have no trouble seeing severity for white patients, but for black patients, noise intervenes between severity and the expression of the symptom. To isolate the effects of miscommunication, we assume that severity is distributed identically for Blacks and Whites ($Z \sim N(\mu, \sigma^2)$). For Whites, the symptom the doctor observes, S, is identical to the patient's severity, Z (the signal perfectly indicates severity). For Blacks, $S = Z + \varepsilon$, where $\varepsilon \sim N(0, \sigma^2_\varepsilon)$ and $\sigma^2_\varepsilon < \infty$. Only for a black patient does the symptom include noise, captured by the ε term.

Seeking to maximize each patient's expected health outcome, the doctor's strategy consists of selecting a threshold severity level S^*, and recom-

mending treatment to all those patients with severity high enough to exceed that threshold. The doctor determines the threshold by setting (1) equal to 0. For Whites, since $\beta = 1$ (or $\sigma^2_{\varepsilon W} = 0$), the doctor recommends treatment whenever $S(= Z) \geq 0$. In the case of Blacks, the doctor's strategy consists of recommending treatment whenever the observed signal, S, exceeds the threshold S^*_B:

$$S^*_B = \frac{-(1-\beta)\mu}{\beta} \tag{2}$$

All Whites who have a positive benefit from treatment get treated, and all Whites with a negative benefit from treatment do not get treated (this is as before in the benchmark case). For Blacks, noise prevents the benevolent doctor from matching treatment to benefit with such precision. Doctors must make a decision only on what they see, the signal. Some Blacks with a high true severity will have a very low value of ε and fall below the signal threshold. Some Blacks with low true severity will emit a misleadingly high value of the signal because their ε is high. The criterion represented by (2) is the best choice of signal cut off for Blacks given the noise content of the signal. Even with the cut off optimized in terms of Blacks' expected benefit, treatment for Blacks is subject to mistakes.

The noisy signal reduces the value of the medical encounter to Blacks. For a white patient with severity Z, the expected benefit is: Z if $Z>0$ and 0 otherwise. For a black patient with severity Z, the expected benefit is:

$$Z \Pr(S > S^*_B | Z) = Z\Phi\left(\frac{Z}{\sigma_\varepsilon} + \frac{\sigma_\varepsilon}{\sigma^2}\mu\right) \tag{3}$$

where $\Phi(\cdot)$ is the standard normal distribution. For the black patient $0 < \Phi(\cdot) < 1$, implying that Blacks with any Z always face a risk of being misdiagnosed and mismatched to treatment. If $Z > 0$, the expected benefit from

treatment is lower for the black patient, since there is a positive probability that the doctor will deny him treatment when he would have benefitted from it. If $Z < 0$, the expected benefit is also lower, since there is a positive probability that the patient will end up being assigned to treatment that turns out to be harmful. The force driving this result is the weaker information content of the signal of severity in the case of Blacks.

While there is a clear disparity in terms of expected outcome in the case of a noisy signal, the picture in terms of disparities in service use is less one-sided. From (2) we can observe that Blacks will be more likely to be assigned to treatment than Whites whenever the treatment is beneficial to the average patient ($\mu > 0$) and will be less likely to be assigned to treatment in the opposite case. Even though Blacks might in some circumstances get more treatment with a noisy signal, it is still a mismatch of treatment to need. See Balsa and McGuire (forthcoming) for further consideration of this issue.

Consider now the fairness and efficiency of the doctor's decisions. The allocation described by (2) is unfair: race matters to the outcome. Comparing two persons with the same characteristics (only Z here), the expected outcome is worse for a Black than for a White. The allocation described by (2) is however efficient given the information available: the expected benefits are maximized for both Blacks and Whites and there is no way of changing the allocation without worsening the health outcomes of black patients, white patients, or both.

A further implication of miscommunication is that minorities might react to the lower value of medical care by demanding fewer health services. The model above can be easily extended to include a search cost of treatment that varies across patients. With such a cost, Blacks will go less to the doctor

or comply less with treatment recommendations than Whites because they expect lower benefits from treatment (Balsa and McGuire, forthcoming).

4.2 Racial Categorization as a "Business Necessity"

Suppose now that the means of the underlying severity distributions differ by race; specifically $Z \sim N(\mu_B, \sigma^2)$ for Blacks and $Z \sim N(\mu_W, \sigma^2)$ for Whites, with $\mu_B < \mu_W$. The doctor is aware of these different means. Again, however, the doctor cannot observe Z, but only a symptom or signal of severity, S. The signal $S = Z + \varepsilon$, with $\varepsilon \sim N(0, \sigma_\varepsilon^2)$ but this time the distribution of the noise is identical for Blacks and Whites. The doctor will be impelled by "business necessity" to treat Blacks and Whites with the same severity differently.

As before, the threshold chosen by the benevolent physician is, $S_i^* = \dfrac{-(1-\beta)\mu_i}{\beta}$, where β is the same for both groups of patients. The difference between each group's threshold is given by:

$$S_B^* - S_W^* = \frac{(1-\beta)}{\beta}(\mu_W - \mu_B) \tag{4}$$

While the optimal threshold in a framework with complete information would be $Z^* = 0$ for both groups, because of uncertainty, the doctor will find it optimal to set a lower threshold for the group with a higher mean severity (i.e., set a lower threshold for Whites than for Blacks). The higher the noise, the bigger the difference between the thresholds. This type of disparity has been referred to as a "business necessity" (Borooah, 2001), and is closely related to the literature on "racial profiling" (Knowles, Persico and Todd, 2001). Again, the expected value of treatment for a patient with severity Z is given by (3). When doctors discriminate by race for business necessity

reasons, white patients do not always fare better than black ones. In the miscommunication framework, the likelihood that a doctor misdiagnoses the patient's condition is always higher for Blacks, no matter if the patient is "healthy" ($Z < 0$) or "sick" ($Z > 0$). When "business necessity" is behind disparities, and $\mu_W > \mu_B$, the doctor is more likely to misdiagnose black patients who are "sick" (not assign treatment when the patient would benefit from it), but less likely to misdiagnose black patients who are "healthy". Whites that should not receive treatment are more likely than Blacks in the same situation to be erroneously recommended for care.

The doctor's discrimination equalizes the marginal expected benefits from treatment across the different racial groups. See Figure 3. The upper graph shows, for any given signal S, the benefits the doctor expects white patients and black patients to receive from treatment. Since the doctor is Bayesian and weighs both the observed signal and the prior about the severity distribution, expected benefits of Whites (whose prior is higher) are shifted by a constant above those of Blacks. The threshold that maximizes each group of patients' expected benefit is that which makes the expected benefit function equal to zero. The lower graph shows the fraction of Whites and Blacks receiving treatment given the threshold signal chosen by the doctor. We can see that, with the chosen thresholds, some white and black patients with the same severity (and also the same signal) are treated differently. Concretely, a white patient with a signal between S_W^* and S_B^* is recommended treatment whereas a black patient in the same severity interval is not.

The outcome of racial profiling is unfair, because race matters in the decision. Otherwise identical Blacks and Whites, including those emitting the same symptom-signal, are treated differently. But the allocation rule

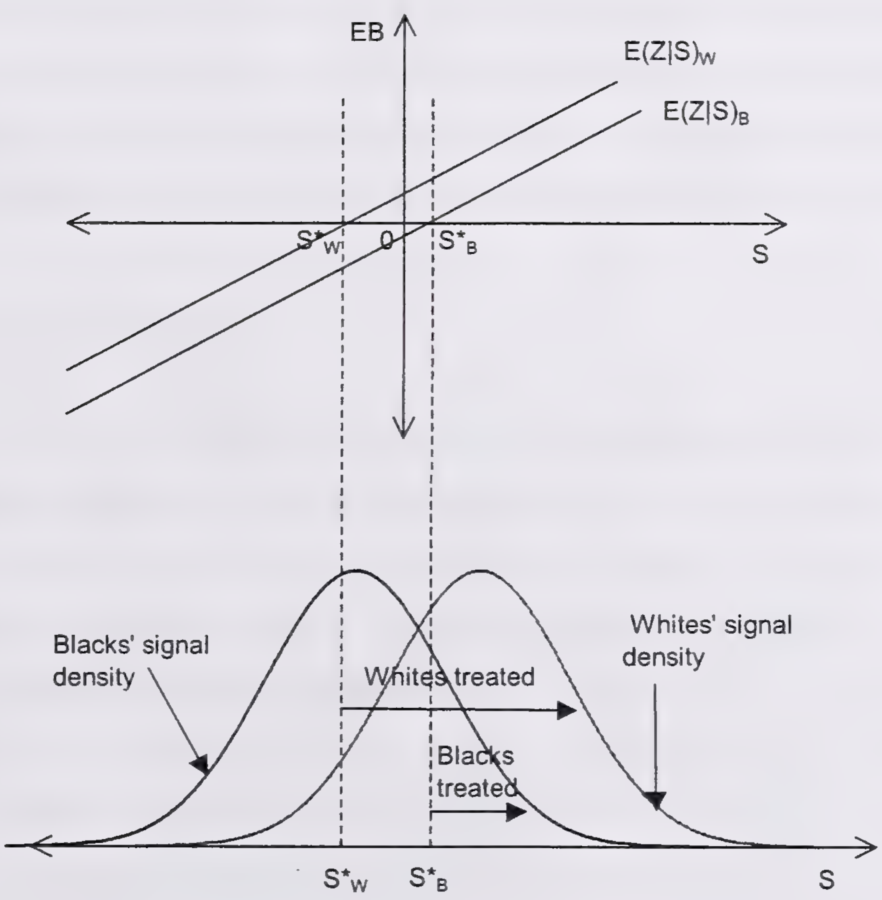

Figure 3: Using Race as a Category to Improve Diagnosis

is efficient. Social welfare is maximized given the information available. If the doctor were to employ a common threshold for Blacks and Whites, the doctor would misdiagnose more patients in each group and the value of medical care would be reduced for the average black and white patient.

The "business necessity" mechanism generates disparities even if the doctor is benevolent and even if the doctor's priors about the distribution of the underlying severity in the two populations are accurate. It is natural to ask, however, how inaccurate physician beliefs might lead to disparities. We consider this under the name of "stereotyping" in the next section.

5 Stereotypes

We now isolate a third possible source of disparities within the clinical encounter: stereotypes about minority patients held by physicians. Stereotyping is a term used by social psychologists to refer to "the process by which people use social categories (e.g., race, gender) in acquiring, processing, and recalling information about others" (Dovidio, 1999, p. 804). Williams and Rucker (2000) argue, based largely on studies outside of health care, that negative stereotypes about minorities are an important explanation for health care disparities. There is evidence that many white Americans attribute negative stereotypes to Blacks (Davis and Smith, 1990), and that negative stereotypes translate into discriminatory behavior of Whites towards Blacks in housing, education, and other areas (Hilton and von Hippel, 1996). In a health care context, van Ryn and Burke (2000, p. 814) argue that "Physicians may be especially vulnerable to the use of stereotypes in forming impressions of patients since time pressure, brief encounters, and the need to manage very complex tasks are common characteristics of their

work." These authors studied physician beliefs about patients in 618 medical encounters. After controlling for patient socio-economic status and other factors, they found that physicians believe Blacks are more likely to abuse drugs or alcohol, less likely to comply with medical advice, and less likely to participate in rehabilitation therapy.

Stereotypes can arise and be sustained for different reasons. In contemporary social psychology, the prevailing approach to stereotypes is cognitive, viewing stereotypes as a way to "simplify and organize social information" (Dovidio, 1999), an element of what everyone does to avoid paralysis in a complex world. Beliefs about outgroups tend to be negative and exaggerated, stemming from individuals' propensity to associate favorable characteristics to their own ingroup (Ashmore and Del Boca, 1981). Stereotypes can evoke reactions in the target group that confirms the original negative belief, a phenomenon Loury (2001) believes to be central to racial issues in the US. This approach fits well with the economic approach to stereotypes that requires that a belief held by a (rational) economic actor be confirmed in market equilibrium (Arrow, 1973). In this section we show how a negative stereotype about Blacks -"Blacks can't be relied upon to comply with treatment recommendations"- can become a self-fulfilling prophecy and lead to disparities in treatment.[9]

We assume that doctors observe severity accurately (thus setting aside problems of communication that are worse for Blacks than Whites) and that

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[9] We thus do not consider stereotypes as a device an individual or group uses to enhance personal and ingroup esteem at the expense of others. Analysis of stereotypes from this perspective would put no restriction on beliefs in terms of the information available to the individual. Stereotypes satisfying a need for self-esteem could be a basis for the "prejudice" that we studied in section 3 above.

doctors value the net benefit of treatment the same for both groups (setting aside prejudice). To make a role for stereotypes, we must enrich the model of the medical encounter. We assume that the benefit of treatment depends on decisions by the doctor and the patient, as well as on the severity of the patient's condition. The doctor makes a decision to take effort to be conscientious in treatment of a patient, and the patient makes a decision about whether to comply with the doctor's recommended treatment regimen. Conscientiousness and compliance both contribute positively to outcome. Although doctors can observe severity, they must make a decision about the effort they choose to put in prior to observing whether patients comply. Patients do not directly observe whether or not doctors have been conscientious with them. This is a setting in which stereotypes - beliefs held by the doctor - can turn a situation of *a priori* equality into one of *ex post* disparity. In what follows, Blacks and Whites will be completely identical in all respects. A "stereotype" is a belief doctors hold about the likelihood that patients will comply with recommendations. We do not explain where these beliefs come from, but we do show that negative beliefs about Blacks can be self-fulfilling.

5.1 Stereotypic beliefs can cause disparities

We show how stereotypes can generate disparities by an example. Benefits from treatment depend on the patient's severity, Z, and on the doctor's effort and the patient's willingness to cooperate with the diagnosis/treatment process. Let e^d be doctor's effort and e^p be the degree of patient's cooperation. Doctor's effort e^d can take the values of $\{0, 1\}$ and patient's effort $e^p \in \{e_L, 1\}$, with $0 < e_L < 1$. We modify the benefits from treatment to

allow for doctor's and patient's effort to have an impact on treatment outcomes. A patient with severity Z whose level of cooperation is e^p derives a gross benefit from treatment of Ze^pe^d when the doctor's level of effort is e^d. Additionally, both doctor and patient have to incur certain costs when making high effort and when cooperating respectively. We denote the doctor's cost of high effort as c^d and the patient's cost of cooperating as c^p (we normalize the costs of low effort/no cooperation to zero). The doctor maximizes the patient's gross benefit from treatment net of his own cost of effort. White and black patients are identical in terms of severity, costs and benefits from treatment. The stereotype we analyze is the doctor's belief that "Whites cooperate in treatment, but Blacks do not cooperate".

The patient's payoffs are given by the gross benefits from treatment net of the costs of cooperation. The following table describes the game's payoffs for a patient with severity Z:

		Doctor	
		High effort	Low effort
Patient	Cooperate	$(Z - c^p), (Z - c^d)$	$(-c^p)$, (0)
	Don't cooperate	(Ze_L) ,$(Ze_L - c^d)$	(0) , (0)

Table 1: Doctor Stereotypes Lead to Multiple Equilibria[10]

We assume that $(Z - c^d) > 0$ but $(Ze_L - c^d) < 0$, part of what needs to be true here for a stereotype to be sustained. It is worthwhile for the doctor to be conscientious if the patient cooperates with treatment $(Z - c^d) > 0$, but it is not worthwhile if the patient does not cooperate $(Ze_L - c^d) < 0$. Similarly, on the patient's side, for the stereotype to be sustained, the optimal strategy

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[10] The first expression in each cell stands for patient's payoffs and the expression after the coma stands for doctor's payoffs

for the patient must be to cooperate if his cost of cooperation is sufficiently low and the doctor puts high effort ($Z - c^p - Ze_L > 0$), and not to cooperate otherwise ($-c^p < 0$). Both (Cooperate, High Effort) and (Don't cooperate, Low effort) are Nash equilibria of the simultaneous game described above. Payoffs like the ones shown above are plausible and can sustain different equilibria for black and white patients. Disparities result if white patients end up in the (Cooperate, High Effort) equilibrium but black patients end up in the (Don't cooperate, Low Effort).[11] Note that in spite of the fact that black and white patients are identical in all respects, and doctors are without prejudice, the doctor's stereotype of the noncompliant black patient is confirmed by the doctor's experience in equilibrium.

An allocation resulting in disparities because of stereotypes (a "coordination failure" in the language of game theory) is both unfair and inefficient. It is unfair because identical patients (same severity, same costs) are being treated differently. It is inefficient because Blacks for whom it would be efficient to cooperate - those Blacks with low costs of cooperation - are driven into non-cooperation by the doctor's beliefs.

More subtle (and realistic) forms of stereotypic beliefs, like those reported by van Ryn and Burke (2000) that Blacks are "less likely" to comply, can also be sustained in equilibrium with the restriction that doctor's beliefs must be confirmed by experience. Coate and Loury (1993a) have shown this in a labor market context, which can be adapted to a health care exchange.[12]

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[11] Another application of the same idea is the following. Say doctors have two kinds of treatments to assign patients to, one of them more expensive but also more effective than the other. If the effectiveness of the superior treatment depends on patients' compliance, and doctors believe Blacks to be less compliant than Whites, then they might end up assigning Blacks at a lower rate to the superior treatment.

[12] Coate and Loury's (1993a) analysis of stereotypes in the labor market can be directly

6 Implications for Policy

Two general types of policies have been proposed to address disparities. The first consists of improving the information available to agents in their decision-making processes. We call this approach an "information-based" policy. Promoting cultural competency, interpreter services, recruitment and retention policies, training, coordinating with traditional healers, use of community health workers and inclusion of family members (Brach and Fraser, 2000) all belong to this type of policy. The other proposed intervention to deal with disparities is to require that the same criteria for treatment be applied to Blacks and to Whites, based on an argument of civil rights: Blacks are entitled to the same treatment as Whites. A rule for literal "equality" in rates would not be feasible to implement. What would be feasible would be a rule that puts the burden of proof on a provider (a hospital, say) to demonstrate that if rates of treatment are different, there is a medical reason to justify the difference. The legal burden of proof falls this way in the context of potentially discriminatory practices in labor markets.[13] We refer to such a policy as a "rule-based" policy because it requires doctors' assignment of patients to treatment to satisfy a certain rule. The legislation enacted in Title VI of the 1964 Civil Rights Act is an example of

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extrapolated to health care by relabelling the agents' strategies and using the payoffs in Section 5.1. In the health care setting, the patient's decision to cooperate or not with the doctor is equivalent to the worker's strategy to invest or not in education. Similarly, the doctor's decision to put high effort or low effort in the treatment corresponds to the employer's decision to assign the worker to a high or a low skill task.

[13] See Epstein (1992) for discussion of the application of the 1991 Civil Rights Act to labor markets. Bloche (2001) contains a general discussion of the value and limitations of rule-based policies in the context of health care disparities.

a rule-based type of policy. [14] We show in this section that while rule-based policies are the obvious solution to disparities caused by prejudiced doctors, when information problems are at least partly behind clinical disparities, the analysis is more complex.

6.1 Information can help reduce disparities stemming from miscommunication but rules run a risk

We begin by analyzing the consequences of policy in the case of clinical uncertainty. We show that when disparities are due to a less informative interaction between minorities and the doctor, the policy to implement is one that helps improve the information content of minority patients' signals. Enforcing rules in the doctor's decision-making, without changing the information available to the doctor, will have detrimental results for both black and white patients.

Mismatches of treatment to needs decrease as the noise in the signal falls. This follows directly from (3) in Section 4.1. Improving doctors' ability to interpret symptoms from minority patients (moving communication more towards the white level) increases expected outcomes. Improving doctors' communication skills, implementing language programs, or even modifying clinical tests to better pick up key information from ethnic and racial minority patients are among the policies that have been suggested (Caudle, 1993).

A rule-based policy, on the other hand, will not only fail to improve

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[14] Title VI prohibits discrimination on the basis of race, color or national origin by recipients of "federal financial assistance". While limited in scope by the requirement of federal assistance, Title VI has a broad impact in health care given the enormous role that federal financial assistance plays in the health system (Rosenbaum et al., 2000).

the situation of black patients, but will probably have negative implications for the average health outcome for both groups. If severity is distributed identically for Blacks and Whites, a rule-based policy that requires doctors to assign black patients to treatment at the same rate as Whites, is equivalent to requiring that doctors apply the same signal threshold (to qualify for treatment) for patients of either group.

To analyze the welfare implications of such a policy we must construct for each group the expected benefits from treatment given a certain threshold. For Blacks, this expression is:

$$EB(\tilde{S}, \beta_i) = \left[1 - \Phi\left(\frac{\tilde{S} - \mu}{\sigma_{\mathrm{Si}}}\right)\right] \mu + \beta_i \sigma_{\mathrm{Si}} \phi\left(\frac{\tilde{S} - \mu}{\sigma_{\mathrm{Si}}}\right) \tag{5}$$

where $\tilde{S}$ is an arbitrarily chosen threshold and σ_{S_i} is the variance of the signal ($\sigma_{\mathrm{Si}}^2 = \sigma^2 + \sigma_{\varepsilon_i}^2$).[15] For Whites, welfare is measured by replacing β_i in (5) with 1 and $\sigma_{S_i}^2$ with σ^2. Black patients' welfare is maximized when the physician chooses $S_B^* = -\frac{(1-\beta_B)\mu}{\beta_B}$ while white patients' welfare is maximized when $S_W^* = 0$. It is easy to show that each group's welfare function is concave at the optimum.[16] Thus, *any* common threshold must make at least one group worse off. The best single cutoff under a rule-based policy maximizes the expected benefit to the population as a whole.[17] This

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[15] Note that $EB(\tilde{S}) = \int_{\tilde{S}}^{\infty} [(1-\beta)\mu + \beta S] \frac{1}{\sigma_S} \phi\left(\frac{S-\mu}{\sigma_S}\right) dS$ which after some manipulation, involving the use of the truncated normal distribution, can be expressed as (5).

[16] $\frac{\partial^2 EB(S_i^*, \mu)}{\partial \tilde{S}_i^2} = -\phi\left(\frac{\mu}{\sigma_S \beta_i}\right) \beta_i < 0$

[17] Let λ be the fraction of Whites in the population. Under a rule-based policy, the doctor will set S^* so that it maximizes: $(1-\lambda)\left\{\left[1 - \Phi\left(\frac{\tilde{S}-\mu}{\sigma_{S_b}}\right)\right]\mu + \beta_B \sigma_{S_b} \phi\left(\frac{\tilde{S}-\mu}{\sigma_{S_B}}\right)\right\} +$
$\lambda\left\{\left[1 - \Phi\left(\frac{\tilde{S}-\mu}{\sigma_Z}\right)\right]\mu + \sigma_Z \phi\left(\frac{\tilde{S}-\mu}{\sigma_Z}\right)\right\}$
The optimal threshold can be shown to be $S_{BW}^* = \frac{-(1-\lambda)(1-\beta_B)\mu}{(1-\lambda)\beta_B + \lambda}$, a compromise

compromise makes both groups worse off. Figure 4 illustrates the effect of choosing a common threshold in the case in which Blacks and Whites share the same distribution of severity but there is noise in the signal. Choosing the best common threshold S^*_{BW} decreases the expected benefit to both groups below that obtainable if separate thresholds, S^*_B and S^*_W, can be used.

Consider the fairness and efficiency of a rule-based policy. As just noted, such a policy is inefficient for both groups. A rule-based policy will on average reduce the value of the health care encounter for Blacks and Whites. Nor is a rule-based policy fair. A rule-based policy achieves parity in the application of symptom criteria, but this is not the same fairness as we have defined it above. A rule-based policy that optimizes the choice of a signal threshold for the whole population still leaves Whites better off. Indeed, for any rule-based threshold that is a compromise between that for Blacks and Whites, Whites are better off. It is possible to achieve a "fair" policy in the sense of equalizing expected benefits given a signal, by moving the signal threshold far enough away from the regions in which the maxima occur (see Figure 4), but this is destructive for both groups. In sum, when disparities are caused by increased clinical uncertainty in reading the symptoms from Blacks, a rule-based policy is never efficient. A rule-based policy is never fair except in the case of a policy strictly dominated in efficiency terms. [18]

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between the optimal level for Whites (0) and the optimal level for Blacks in the discriminatory equilibrium.

[18] A Rule-based policy will also be inefficient when disparities are generated because of business necessity. Each group's welfare function is concave at the optimum threshold chosen by the doctor.

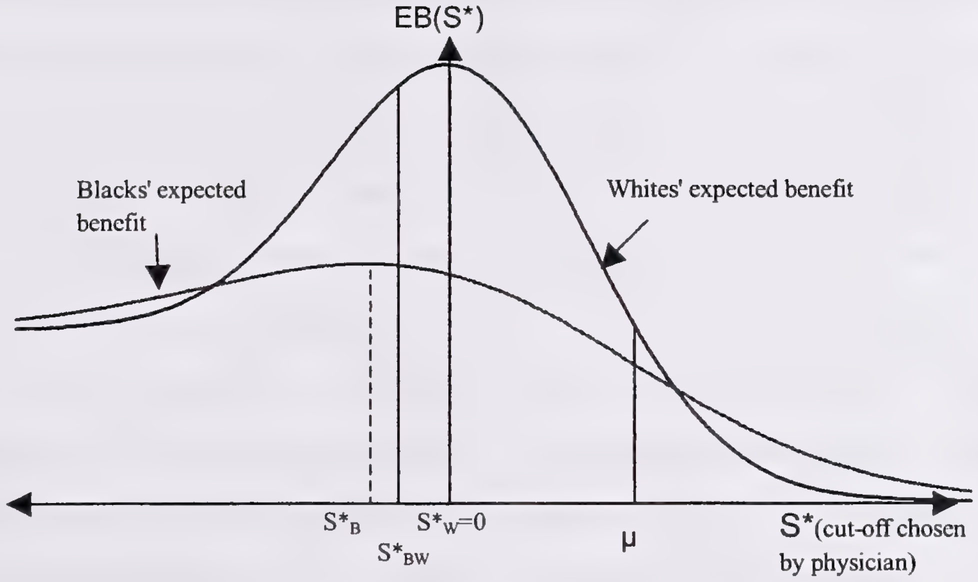

Figure 4: A Noisy Signal Means Blacks' Efficient Cutoff Differs From Whites'

6.2 The limited scope of information-based policies at combating prejudice and stereotypes

Ignorance and unfamiliarity as sources of stereotypes and prejudice have received ample attention in the social psychology literature (Fiske, 1998). The underlying proposition is that infrequency of contact fosters ignorance, which promotes anxiety and frustration, assumed dissimilarity and stereotyping, together leading eventually to prejudice. Information, in the form of sustained personal experience countering the stereotype, has been shown in some cases to change beliefs (Fiske, 1998). If this were the case in health care, multicultural education that stressed understanding of group differences might eliminate stereotypes or alleviate prejudice by promoting empathy and understanding between doctors and minority patients. However, social psychologists acknowledge that the scope of informational policies in

the fight against prejudice and stereotypes is limited, even when lack of information and ignorance are recognized as the main causes of biased or prejudiced behavior. People don't always use information objectively. Negative information is more powerful than positive information; its rarity and unexpectedness give it more weight. Additionally, it is unclear how a policy aimed at changing the experience of doctors on a large scale would be implemented.[19] We showed in Section 5 (stereotypes) that doctors' beliefs can relegate Blacks to a "bad equilibrium" - one that is inefficient in comparison to the equilibrium for Whites, and one that is unfair. The problem is that the bad equilibrium can be a stable equilibrium: black patients are acting in their self interest, given doctors' beliefs and actions, when they show less cooperation. Stability of the equilibrium implies that black patients'rational response to a unilateral favorable change in beliefs of doctors would work to reestablish the initial bad equilibrium, unless the change is very large (and thus hard to achieve). A small change will appear futile and fail to dislodge the equilibrium. The negative stereotypes will tend to be restored. The implication of our analysis is that information-based policies may need to convince both doctors and black patients to change their beliefs about the other party, and that these changes would have to be non incremental to succeed in establishing a new pattern of interaction. Information-based policies in just one area of social interaction -health care- are very unlikely to be powerful enough by themselves to make a difference when prejudice or stereotyping are on the basis of the discriminatory behavior.

It seems clear that if doctor prejudice/stereotypes are among the causes

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[19] As far as we know, there is very little work in the social sciences that addresses the problem of how to redress inefficiencies and inequities associated with the coordination failure caused by stereotypes. Our comments here should be regarded as speculative.

of disparities, some form of rule-based policy is necessary to address the problem. A rule-based policy will be enforceable if it depends on a verifiable activity.[20] Suppose the rule to be satisfied by any doctor is that the fraction of black patients assigned to a particular type of treatment should be equal to the fraction of white patients assigned to that treatment. This is analogous to an "equal opportunity" policy in labor markets, analyzed by Lundberg (1991), where employers are required to promote the same share of black and white workers to higher grade jobs. The doctor faces now a restricted problem: the doctor has to make a decision about treatment subject to an equal opportunity constraint.

Consider the implications of a rule-based policy in the stereotyping model analyzed in Section 5. When doctors have identical beliefs about black and white patients the equal opportunity constraint is not binding. Since an equilibrium with identical beliefs is always a possible outcome of the unconstrained problem (in section 5.1, both groups could end up in the cooperate, high effort equilibrium if doctors believed that all patients were cooperative) and because it satisfies automatically the constraint of the restricted problem, it is also a possible outcome of the problem with an equal opportunity policy. However, if beliefs are different for each group, then the constraint is binding in the restricted problem. If λ is the number of white patients in the population, a pure strategy for the doctor will be to provide "high effort" treatment to every patient if $\lambda(Z - c^d) + (1 - \lambda)(Ze_L - c^d) > 0$ and to provide "low effort" treatment to everyone if that expression es negative.

In the simple game described in section 5.1, an equilibrium that entails identical beliefs about groups is the only possible equilibrium once the policy

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[20] Rule-based policies have been subject to formal analysis in the labor literature (Coate and Loury, 1993a and 1993b).

is introduced. Then, a temporary policy will produce the permanent benefit of ensuring that doctors will respond equally to both groups in a new equilibrium (and no further enforcement will be necessary). In this case, if the equilibrium for Blacks is initially Pareto dominated and λ is sufficiently high, a policy that enforces the same outcome for both groups can change the incentives to cooperate for black patients and progressively change the doctor's beliefs about this group. A rule-based policy will then improve economic welfare by shifting the Black equilibrium from low beliefs to high beliefs. [21]

Coate and Loury (1993a) analyze the implications of a rule-based policy (affirmative action) in a stereotypic equilibrium in which the employers (physicians) are Bayesian and infer from a signal the likelihood that the employee (patient) has invested (cooperated). Although affirmative action is shown there to improve welfare for minorities, its effect on the underlying stereotypes held by employers is not straightforward. The authors show that there are circumstances under which affirmative action policies not only fail to eliminate negative beliefs but may worsen them. This may occur if preferences induce employers (doctors) to "patronize" the favored workers (patients), which in turn undercuts their incentives to acquire necessary

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[21] When prejudice is behind disparities, enforcing a policy that requires the same rates of assignment to treatment for both groups will result in an improvement of health care conditions for minorities and in a fair outcome. The ideal rule would require that doctors set the same threshold for Whites than for Blacks, at $Z = 0$. Welfare for black patients would improve then at no cost for white patients. However, it is likely that Z is hard to monitor by a regulator. In that case, the only policy that might be enforced is one that requires equal treatment rates for both groups. Although such a policy would improve welfare for Blacks, the improvement would be smaller than that obtained with the ideal rule and come at a cost of a decreasing welfare for Whites.

skills (to cooperate with treatment). In that case, the efficiency effects of a rule-based policy will not be clear, and even worse, the policy may encourage the race-conscious behavior of doctors (if stereotypes get even more negative with the policy). A rule-based policy, while solving some fairness and efficiency issues, causes other efficiency problems to get worse.[22] Complementing these policies with information-based actions may be a way to attack the issue at its root by ensuring stereotypes are also being eliminated.

7 Conclusions

How the interaction between doctor and patient contributes to disparities is not well-understood. The crudest and simplest case is when a doctor indulges a prejudice against minorities and authorizes less treatment for a minority than for a white patient. The emphasis in the empirical literature on disparities documenting lower rates of health care use would seem to accord with this underlying hypothesis of what is going on between provider and patient. This case is (conceptually at least) also a simple one in terms of policy: rule-based actions are the way to go.

A major goal of this paper, drawing from the rich literature in labor economics, was to point up another set of possibilities for the way disparities might come about in the clinical exchange, consistent with the doctor or other health care provider having an equal regard for the health of white and minority patients. Having difficulty understanding symptom reports

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[22] A further implication of an "equal opportunity" policy is that it can increase inefficiencies if there are real underlying differences between the two groups. Efficiency would decrease then due to the restrictions imposed to the use of group membership information in the doctor's decision-making process.

from minority patients, or holding beliefs about minorities that lead the doctor to make different decisions for minorities, are distinct from prejudice and lead to disparities through more subtle mechanisms. Greater clinical uncertainty and stereotypes are at base information problems. Designing effective policy in these cases is more difficult. For one thing, policy must recognize that doctors and patients may be "doing the best they can" given the information available to them. Information interventions may be more on target and safer when uncertainty is the culprit. Rule-based policies, such as requiring doctors to act in a race-blind fashion, when race conveys information that can help the doctor decide what to do for the patient, can make matters worse for the patients the policy is designed to help.

We acknowledge that we are only able to make general comments about policy with the conceptual approach employed in this paper. Our analysis is better suited to identifying cautions than for prescribing actions. All three things may be going on at once – and others besides. The mix of causes is likely to differ in different clinical areas, geographic areas, and types of health care systems, calling attention to the importance of empirical research.

Almost without exception, empirical research on disparities seeks to document "how much less" minorities are getting. We want to encourage empirical research of another type. Based on explicit formulations (hypotheses) about the mechanisms that might be responsible for disparities, research should test the relative importance of the various ways disparities can come about from the clinical encounter. In our earlier paper (Balsa and McGuire, forthcoming) we set out a number of testable implications of increased clinical uncertainty. For example, if physicians' decisions about minorities are more influenced by "priors" rather than information collected in a clinical encounter, the range of recommendations made to minority patients should

be more restricted than for white patients. (This is not a matter of more or less.) Expanding this framework to include testing for the presence and effect of stereotypes is also warranted.

The utility of this line of research is twofold. First, disparities in health care services may not (mostly) be a matter of "less." With the exception of the simple prejudice mechanism, the implications of the other mechanisms may be more or less in terms of quantity of services. The importance of disparities in services is that minorities may have health care services poorly matched to their needs. This is a more general problem than simply getting less. Put it this way: minorities getting no less than Whites on average does not rule out disparities. A focus on the question of matching needs to services is a more general and pertinent framework than simply the getting-the-same-quantity framework.

Second, this type of research is what policy makers need. The research to date on disparities does not differentiate among the various mechanisms. As we argued here, making a good choice about what to do about disparities should be based on a good idea of what causes the disparities. The broad distinction in causes is between information and prejudice, corresponding to a broad distinction in policy between information-based and rule-based interventions. In our view, assessing how much of disparities can be set down to misinformation, and therefore responsive to policies to improve information and communication, is the most immediately useful thing empirical research can do for policy.

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Why isn't health care colorblind?

Two Harvard doctors release a massive report arguing that blacks face a legacy of racism, even at the doctor's office

By Richard Saltus, Globe Correspondent, 3/26/2002

Only 35 years ago American blacks were guaranteed their civil rights and hospitals were legally required to end racial desegregation. The notorious Tuskegee experiment, when white scientists purposely left hundreds of African-American patients untreated for syphilis over decades, stopped only when it was exposed in 1972. Slavery itself was abolished less than 140 years ago.

Given such relatively recent examples of overt racism, the poor health of African-Americans compared to whites in 2002 is hardly surprising, say two Harvard physicians, who contend in a new, heavily documented chronicle that blacks have systematically suffered from inferior medical care ever since their arrival in chains from Africa.

"Treating patients differently on the basis of race and class is a 383-year-old tradition in American medicine," said Dr. W. Michael Byrd, who, with his wife, Dr. Linda A. Clayton, just published the second volume of their work, "An American Health Care Dilemma." The sweeping survey by these two doctors, both with the Harvard School of Public Health, is widely regarded as the most persuasive and detailed account of blacks' troubled relationship with US health care.

From the time of slavery, US blacks have borne a "black health deficit" that has yet to be overcome, they say, and it's engendered myths that black patients simply don't fare as well as whites.

At a time when the $1.5 trillion US medical system can do more for sick people than ever before and has ever-greater ambitions - aiming to clone human repair tissues and conquer diseases like cancer - blacks, having poorer access to care, are being left behind at an even faster clip than before, Byrd said.

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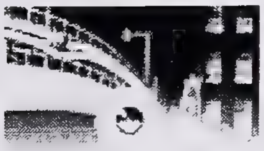

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"Blacks stopped making progress. As the rest of the population continues to make progress, blacks do worse in relative terms," he said during a recent interview at the couple's home in Mission Hill in Roxbury. "That's why the disparities are widening: To not have health care 70 years ago didn't mean nearly as much as it does in 2002."

Their survey is published as one new study after another confirms the racial divide in health care. A government report last week from the Institute of Medicine confirmed what Byrd and Clayton and others have been saying: That even when socioeconomic factors are accounted for, blacks still receive inferior health care and are sicker. (Byrd was involved in the institute's study.) On March 13, the Harvard School of Public Health issued a similar report about the disparity in health care delivered to whites and blacks.

Physicians, however, hold seemingly contradictory opinions about the cause. Last week, the Kaiser Family Foundation released poll results in which 65 percent of doctors (more than 2,600 were surveyed) acknowledged racial disparities in treatment for heart disease, and 65 percent said it was true for AIDS treatment. Yet more than two-thirds said that the health care system "rarely" or "never" treats patients unfairly because of race. In sharp contrast, African-American physicians disagree with their collegues. Nearly 80 percent of them believe race and ethnicity affect how people are treated at least somewhat often.

Whatever the reasons, the statistics paint a grim picture. Blacks on average currently die five to seven years earlier than whites. More than 50,000 blacks deaths a year are considered "excess" - they wouldn't have occurred if their death rate was the same as that of whites. African-Americans disproportionately sustain heart disease, diabetes, stroke, HIV disease, and some forms of cancer. If these stubborn trends are not reversed, many fear blacks and the poor and other minorities will become a permanent "health and health care underclass."

The chasm is fed by mutual misperceptions and, among blacks, deep-seated distrust of the medical system. Many blacks see physicians only reluctantly, seek help too late for cancers that have already spread, or refuse recommended treatments. While such behavior is self-defeating, it is understandable in people "forced to receive health care in a system that since Colonial times has been largely hostile toward them," Byrd and Clayton wrote.

Their fact-packed book, encompassing more than 1,300 pages in two volumes (the first volume was published in 2000) and with hundreds of references, has entered the policy discussion at a time when racial and ethnic health disparities are a high-profile national embarrassment. In February, Boston health officials voiced dismay at a report that black infant mortality in the city was four times greater in the year 2000 than among whites - a reversal of a previously improving trend. Studies also show that minorities are not only less likely to get high-technology treatments, such as organ transplants and heart-bypass operations, they're also more likely to undergo less-desirable

procedures such as amputations of legs and feet, said the Institute of Medicine report.

Echoing the findings of Byrd and Clayton, the institute's panel found that even people who aren't overtly biased today may display unconscious negative racial attitudes and stereotypes. The report called for spreading awareness of the problem and additional research into the causes of unequal treatment, and more funding for enforcement of antidiscrimination laws.

The panel also stressed the need for more minority health care providers. "An American Health Dilemma" documents the many hurdles faced by blacks since Colonial times in attempting to enter medical schools, practice in hospitals dominated by white doctors, and join mainstream professional organizations such as the American Medical Association.

While blacks make up 13 percent of the US population, only 3 percent of doctors are African-American. Dr. Augustus White of Harvard Medical School and Beth Israel Deaconess Medical Center, who is a rare black in the field of orthopedic surgery, said that, even though the numbers of black physicians has increased in the past several decades, it hasn't changed the black-white ratio significantly.

White, who called the Byrd and Clayton book "terribly important," said he, too, believes there is a "pervasive, unconscious, unrealized bias" against blacks in the mainstream medical system, and said the book should become part of the medical school curriculum.

A persistent "pseudoscientific" belief in the native inferiority of blacks forms another thread of the race problem, the authors say. They traced these ideas back as far as Aristotle and Plato, found them enduring in 19th-century, postevolutionary-theory biology. (Blacks were classified by some experts as closer to tree-living primates than humans.) Symbolic of this view, all-white, all-male medical school classes at the turn-of-the-century often conducted experiments on a room full of black cadavers.

Byrd, 58, and Clayton, 53, are both obstetricians and gynecologists, and have worked on the front lines of urban health care as well as immersing themselves in health policy issues. Byrd, who is a consultant physician at Beth Israel Deaconess Medical Center, has worked on health issues with the NAACP, the National Medical Association and other organizations. Clayton, who is a specialist in gynecological cancer, has consulted with black interest groups and was formerly medical director of the Roxbury Comprehensive Community Health Center. Currently she is associate medical director for the state Division of Medical Assistance.

The spark that was to ignite their nearly decadelong book project occurred when they were both professors at Meharry Medical College in Nashville, Tenn. Byrd for years had been digging into medical history, trying to understand how intelligent, sophisticated physicians could have such a "blind spot" about race to create such a history of discrimination. Clayton, whose

own mother wasn't allowed to bear her child at Duke Medical Center in North Carolina because she was black, joined him in his search.

When they arrived at Harvard in 1991 to obtain master's degrees in public health, they gained an influential supporter and mentor in Robert Blendon, professor of health policy at the School of Public Health. He was impressed by their determination. "The whole health policy community through the 1960s completely ignored the African-American experience," Blendon said. "No one was writing about this."

Tapping a myriad of sources including medical and social history, official reports and journalistic accounts, Byrd and Clayton concluded that blacks have always been treated in a separate and unequal health system. In Colonial times, black slaves already behind the curve in health terms because of the harsh conditions of their ocean voyage and new (to them) diseases encountered in America, got little treatment from medical doctors. So-called "root" doctors, midwives and other traditional healers formed an alternative, slave health subsystem.

The Civil War and Reconstruction were "disastrous" for black health, the authors say, and even in the first half of the 20th century, inequality in health care was the rule. Turned away by many private hospitals, blacks sought care in charity hospitals and clinics that were usually overcrowded and underfunded, creating a "multi-tier" health system. Some plantation owners operated slave hospitals, where most care was conducted by folk healers.

Not until the Civil Rights movement of the 1960s, Byrd and Clayton stated, did significant improvements in black health status occur. With their rights legally guaranteed and Medicare and Medicaid established to provide care for the old and the poor, blacks saw their life expectancy and health measures respond to better treatment. Since then, however, the authors say those gains are being lost as aid programs have lost funding and facilities like community health centers are financially distressed.

The enormous book project was taxing and often done in hours stolen from sleep while Byrd and Clayton were working in a New York hospital. One big obstacle emerged in completing the book - Byrd's own health. A chronic blood-clotting disorder worsened, impairing his heart and lungs and sapping his strength to the point he could no longer write. "In the fall of 1996, he was very ill and we decided to get married," Clayton said. "We cared a lot for each other and we had been through a lot together." The book was completed, but the burden of getting it published rested heavily on her. With Byrd's care taking more of her time, she left the taxing Roxbury job and took her current position with the state.

In desperation, Byrd went to San Diego for an unusual and risky operation to repair his heart and extract blood clots from his lungs. It was successful, but his recovery was long and slow. Today he is tethered to an oxygen bottle and he has to limit his exertion.

In July 2000, the first volume of "An American Health Dilemma" was published, covering the history of race in medicine from antiquity to America in 1900. It won acclaim and a nomination for a Pulitzer Prize. The second volume, bringing the history up to date, has just hit the bookstores.

Byrd and Clayton don't pretend to have the answers to this public health problem, though are pleased to see some state and national panels formed to further examine the issue. Byrd said a universal health care system "would be a great first step."

Certainly the racial and ethnic issues in health care have gained a new high profile: Groups like the state Department of Public Health have established programs to study the problems, and President Clinton launched an initiative to eliminate racial health disparities by 2010. Are they enough?

"We have seen these kinds of efforts before," Byrd said. "It's a start, and it leads to some hope and level of optimism."

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Race/Ethnicity and Cancer Survival

The Elusive Target of Biological Differences

Catarina I. Kiefe, PhD, MD

BLACKS LIVE SHORTER LIVES THAN WHITES IN US SOciety. A newborn in the United States in 1998 had an average life expectancy of 77.3 years if white, 71.3 if black.[1] Furthermore, although life expectancy has increased by about 3 years overall since 1980, the 6-year disadvantage for blacks has not changed. This lower life expectancy, hence earlier mortality, for blacks is a reality that holds true overall but also, with alarming uniformity, across sex, age, and disease subgroups. Potential explanations for this disparity fall into 2 broad categories: environmental/societal/behavioral vs biological/genetic. Underlying the latter is the concept that race/ethnicity is, at least in part, a biological construct.

In this issue of THE JOURNAL, Bach et al[2] present evidence that they interpret as biological differences not explaining the ethnic differences that have been observed in cancer mortality ever since collection of statistics on cancer deaths started. Bach et al identify mortality attributable to a given cancer by separating out age-, race-, and sex-specific overall population mortality due to all causes from the cancer-specific mortality observed in their review of data from 89 cohorts of patients diagnosed with 14 different types of cancer. Because blacks have higher overall mortality in each age and sex group, the overall higher mortality or population mortality of blacks is thus subtracted out. If the mortality residues (ie, the cancer-specific mortalities) no longer differ, then one argues for differences in overall mortality, rather that cancer-specific differences as accounting for differential survival according to race/ethnicity in patients with cancer. In other words, whatever may be different is not different for cancer, but rather for mortality overall.

Do these findings argue against biology as an explanation for the differences? Not necessarily, the interpretation of Bach et al notwithstanding. The authors argue against an explanation that is specific to the biology of the cancer in question. These findings render claims, such as "the pathophysiology of lung cancer differs across race/ethnicity," difficult to defend. Moreover, the findings shift the lack of understanding of the reason for the racial differences from a focus on cancer pathophysiology to a focus on overall mortality. In this, the results of the review by Bach et al are remarkable and novel.

Most measurable human traits exhibit more variability across rather than within races.[3,4] Even distributions of skin color, when measured reproducibly, overlap significantly across racial groups.[5] Therefore, over the past several decades, race as a biological construct became largely discredited among scientists, in favor of race as a sociologic construct, based not on biology but rather on culture, social environment, history—in other words, ethnicity.[6] The lack of scientific foundation for the term *race*, with its implication of biological definition, has been clearly acknowledged by many scientific organizations. Recent examples are an Institute of Medicine report that encourages replacing "race" with "ethnic group" in health-related research[7] and cautionary advice on the use of the word race.[8,9] Yet, the concept of race as a definable biological entity persists in the medical literature.

Is there still some use for race/ethnicity as an indicator of potential differences in biological mechanisms? Arguments in favor are reduced to relying on biological variability associated with skin color, such as the preponderance of blacks among carriers of the sickle-cell mutation (the fact that Mediterranean whites may also carry this mutation is less well known) or the presumably genetically conditioned higher salt-sensitivity in blacks, which may lead to potentially different agents of first choice in the treatment of hypertension according to race.[10] Then, in an era of limited resources, how should decisions be made regarding whether research pursuing the biological/genetic underpinnings of the race/ethnicity concept is more or less worthy of pursuit than research into the environmental/societal/behavioral causes of racial disparities? Where will the most useful information be found to redress the marked imbalance in life expectancy across ethnic groups?

Mapping the human genome holds the promise of an ever-deeper understanding of the contribution of genetics to the observed variability in human traits and its medical consequences. As in other areas of modern medicine, however, this promise has not yet come to fruition in terms of con-

See also p 2106.

Author Affiliation: Department of Medicine, University of Alabama at Birmingham and Birmingham Veterans Affairs Medical Center, Birmingham.
Corresponding Author and Reprints: Catarina I. Kiefe, PhD, MD, Department of Medicine, University of Alabama at Birmingham, 171711th Ave S, MT 700, Birmingham, AL 35205 (e-mail: ckiefe@uab.edu).

tributing to the understanding of race/ethnicity and its implications for the diagnosis, treatment, and prognosis of disease. Scientists and researchers have not yet been able to use genetics to convincingly contribute to the vast literature on racial disparities, and perhaps never will. In the meantime, the same tools of epidemiology and outcomes research that have contributed so much in the past 2 decades to the demonstration of racial disparities in health care are used to begin to understand the why, not just the how, of these disparities, in an attempt to address them.

Of note, racial differences in mortality did not disappear completely in the analysis by Bach et al. For some of the most common cancers, most notably breast cancer, subtracting out population mortality resulted in only a minor reduction in the excess mortality for blacks. However, this finding does not necessarily detract from the above argument. Plausible explanations for racial differences in breast cancer mortality need not invoke a biological pathway. For example, once racial disparities in quality of care for a specific condition are sought, they are almost always found, though not always without controversy. While little is known about racial differences in the processes of care for breast cancer, such differences are likely to exist and may contribute to the observed differences in mortality. Bach et al used only a crude measure of comparability of care across ethnic lines, based on participation in randomized trials and similarity of major interventions (eg, surgery, chemotherapy). Other, more detailed aspects of the process of care (eg, adherence to trial protocols, appropriateness of chemotherapy or follow-up) were not addressed. Thus, the findings by Bach et al by no means exclude the possibility of care actually not having been comparable for blacks and whites.

Because mortality differences in lung cancer, for example, essentially disappeared after looking at comparable strata and subtracting out population mortality, efforts to understand and actions to reduce differential mortality for lung cancer should focus on (1) ensuring that blacks and whites do receive comparable treatment, even when crudely defined as in Bach and colleagues' study; and (2) understanding the broader and more complex issue of racial differences in population mortality. Here, a vast body of knowledge continues to grow by investigating the relationship between socioeconomic factors and health.

Breast cancer is eminently more treatable than lung cancer. That the difference in mortality risk for breast cancer for blacks and whites did not disappear suggests that, even within comparable strata as defined by Bach et al, either quality of care for breast cancer or biology or a combination of the 2 representing gene-environment interactions may differ by race/ethnicity. Even though competing explanations are plausible, seeking such differences in quality of care may be a more fruitful avenue to interventions that address the fundamental racial disparities in mortality than a continued search for elusive biological racial differences that are based on a classification scheme lacking biological definition.

However, mortality is not the only important and measurable outcome. Health-related quality of life (QOL) might be equally important; very little is known about differences across ethnic groups in QOL for patients with cancer. The link between biology and QOL may be even more tenuous than it is for biology and mortality. Furthermore, the link between processes and quality of care vs outcomes may be even stronger for QOL than mortality. Fortunately, initiatives such as the National Cancer Institute's Cancer Care Outcomes Research and Surveillance Consortium (CanCORS) are beginning to explore the relationships between processes of care and QOL as well as mortality.[11] As the results from CanCORS and other efforts become available in the future, they will provide insight into these relationships and how they bear on racial disparities in outcomes for patients with cancer.

In summary, profound disparities in health outcomes based on race/ethnicity are present in US society. Although attributing these disparities to biological differences might partially absolve physicians from the need to address them, the scientific underpinnings for this attribution are weak. It is both scientifically more promising and ethically more demanding to seek the reasons for these disparities in differences at the delivery of care level, because it is more actionable, and at the societal level, because it holds more explanatory power. Bach et al strengthen the argument to focus more intensely on the processes that indeed can be changed.

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Survival of Blacks and Whites After a Cancer Diagnosis

Peter B. Bach, MD
Deborah Schrag, MD, MPH
Otis W. Brawley, MD
Aaron Galaznik
Sofia Yakren
Colin B. Begg, PhD

Context In recent years a theory that cancer biology is different in blacks and whites has gained prominence in reaction to epidemiologic observations that blacks have poorer survival than whites, even when diagnosed with cancer of similar severity. Yet, few studies have evaluated whether lower-quality treatment and shorter overall life expectancy due to a greater burden of other illnesses may explain the survival discrepancy.

Objective To estimate the magnitude of overall and cancer-specific survival differences between blacks and whites who receive comparable treatment for similar-stage cancer.

Data Sources We searched MEDLINE for English-language articles published from 1966 to January 2002 that reported on overall survival for black and white patients treated similarly for cancer.

Study Selection The abstracts or titles for 891 citations were independently examined by 2 authors. The full text was retrieved if the abstract mentioned both black and white patients, made some comment regarding either similarity of treatment received or presented an analysis based on the treatment received, and commented on survival. Studies were included if they included data for at least 10 black and 10 white patients; specified the cohort ascertainment method and what measures were undertaken to minimize loss to follow-up; summarized survival of both blacks and whites using actuarial measures; presented outcomes within stage, adjusted for stage, or based on cohorts with balanced stage distributions; and specified that blacks and whites in the study received similar treatment. We identified 89 unique cohorts in 54 articles that met our inclusion criteria.

Data Extraction Overall survival rates and hazard ratios (HRs) for death for blacks relative to whites were calculated. These were subsequently adjusted for rates of death due to causes other than the cancer under study to determine cancer-specific survival and cancer-specific HRs.

Data Synthesis Results represent 189877 white and 32004 black patients with 14 different cancers. Compared with whites, blacks had an overall excess risk of death (HR, 1.16; 95% confidence interval [CI], 1.12-1.20). After correction for deaths due to other causes, the cancer-specific HR was 1.07 (95% CI, 1.02-1.13). Of the 14 cancers, blacks were at a significantly higher risk of cancer-specific death only for cancer of the breast, uterus, or bladder.

Conclusions Only modest cancer-specific survival differences are evident for blacks and whites treated comparably for similar-stage cancer. Therefore, differences in cancer biology between racial groups are unlikely to be responsible for a substantial portion of the survival discrepancy. Differences in treatment, stage at presentation, and mortality from other diseases should represent the primary targets of research and interventions designed to reduce disparities in cancer outcomes.

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IN THE UNITED STATES, 5-YEAR SURvival after a cancer diagnosis is poorer for blacks than for whites—from 1992 to 1997, the figures were 52% and 63%, respectively.[1] Large, well-designed epidemiologic studies have explored possible reasons for this disparity. Differences in factors such as stage at diagnosis, socioeconomic status, and health insurance coverage, though present, do not appear to be entirely responsible.[2-4] For example, the National Cancer Institute sponsored a Black-White Cancer Survival Study, which compared survival for blacks and whites with cancer of the colon, breast, uterus, and bladder. The poorer survival rates that were observed for blacks with all 4 cancer types persisted after adjustment for both clinical and socioeconomic characteristics.[5-8] Because these factors do not appear to explain the racial difference in survival, the theory that cancers afflicting blacks may be fundamentally more aggressive due to biological or genetic differences has gained prominence.[9-19]

Few studies have been designed to evaluate 2 other factors, unrelated to cancer biology, which may reduce the longevity of blacks with cancer: lesser quality treatment and greater mortality due to other illnesses. Because there are numerous studies documenting differences in the quality of cancer care received by blacks and whites,[20-25] the thought that treatment differences may ultimately underlie the discrepancies in

For editorial comment see p 2138.

Author Affiliations are listed at the end of this article.

Corresponding Author and Reprints: Peter B. Bach, MD, Health Outcomes Research Group, Department of Epidemiology and Biostatistics, Memorial Sloan-Kettering Cancer Center, 1275 York Ave, Box 221, New York, NY 10021.

survival has gained many proponents.[26-28] Moreover, several studies have documented similar survival for black and white patients with cancer who have received similar treatments.[29-33] Rates of death because of cardiovascular disease, diabetes, and other major illnesses are also greater for blacks than whites, leading some investigators to suggest that differences in population mortality should be considered.[29,34-37]

We conducted this study to determine whether there was evidence in the literature of racial disparities in survival between blacks and whites who had received the same treatments for similar stages of cancer. We postulated that if blacks had poorer survival than whites in this context, the survival differences would be explained by the excess rates of deaths due to other causes in blacks. If not, we reasoned that the magnitude of the unexplained survival gap would constitute an estimate of that which may be attributable to differences in cancer biology.

METHODS

Study Overview

We began with a systematic review of all studies in which survival was reported for blacks and whites who had received comparable cancer treatments for similar stages of disease, with the purpose of removing treatment received and stage at diagnosis as explanatory factors. For each pair of cohorts (ie, blacks and whites within a particular study), we converted the reported survival statistics into hazards (death rates) and then calculated the ratio of the hazards for blacks relative to whites. Using the statistical tools of meta-analysis, we then combined these hazard ratios (HRs) across all studies and within predetermined categories of studies.[38]

Next, we used life-table methods to recalculate the hazard of death for each cohort after parsing out the hazard of death due to causes other than the cancer under study. This approach allowed us to estimate the cancer-specific hazards for each cohort, while removing the bias that results from the fact that blacks experience mortality from heart disease, diabetes, and other conditions at higher rates than whites. We then calculated the cancer-specific HRs for blacks relative to whites and generated parallel-summary statistics. Some studies reported cancer-specific death rates based on ascertained cause of death; these estimates were not incorporated in our analyses.

Systematic Review

We found English-language studies that reported on overall survival for black and white patients treated similarly for cancer, not including studies of malignant melanoma, pediatric tumors, malignancies in persons with human immunodeficiency virus infection, or premalignant conditions such as polyps of the colon. We searched MEDLINE (1966 through the third week of January 2002) using the exploded Medical Subject Headings of the National Library of Medicine terms: *neoplasms, cross-cultural comparisons, blacks, racial stocks, negroid race, minority groups, medically underserved area, disease-free survival, survival, survival analysis, survival rate, outcome assessment (health care), outcome and process assessment (health care), follow-up studies, treatment outcome, prognosis* and the key words *neoplasms, cancer, african americans, underserved populations, survival, mortality, treatment outcome*. The abstracts (or titles for those listed prior to 1975) for these citations were then independently examined by 2 authors (P.B.B. and A.G.). The full text was retrieved if the abstract (1) mentioned both black and white patients; (2) made some comment regarding either similarity of treatment received or presented an analysis based on the treatment received; and (3) commented on survival. Agreement on these 3 criteria between the reviewers was 97%. Studies were then screened for potential overlapping cohorts. When encountered, we eliminated the smaller of the 2 overlapping cohorts; this occurred in 2 instances.[39-42] Studies were then included in the analysis if they (1) included data for at least 10 black and 10 white patients; (2) specified what measures were undertaken to minimize loss to follow-up; (3) specified the cohort ascertainment method; (4) summarized survival of both blacks and whites using actuarial measures (eg, median survival, 5-year survival, Kaplan-Meier plot); (5) presented outcomes either within stage, adjusted for stage, or were based on cohorts with balanced-stage distributions; and (6) specified that blacks and whites in the study received similar treatment.

Evaluation of Treatment Within Retrieved Studies

Our confidence in the extent to which treatments received by blacks and whites were comparable within each study was graded based on a hierarchy adapted from Roach and Alexander.[43] Grade 1 studies (the highest grade) analyzed black and white patients who were enrolled on a clinical trial or trials because participants in clinical trials are required to follow particular treatment protocols that are closely monitored. Grade 2 studies reported on the outcomes of black and white patients who had received a particular treatment (eg, all patients undergoing resection of stage I non–small cell lung cancer), allowing for within treatment group evaluation of survival. Grade 3 studies used statistical methods to control for treatment within a population of patients who received different treatments. The method could simply involve demonstration that similar proportions of blacks and whites in the study received the same treatments. Grade 4 studies presented outcomes for black and white patients in which the treatment was likely to be comparable (but was not observed to be so) because patients were all treated either within the same institution or within culturally similar institutions. Examples of the latter group include multiple sites within a single health maintenance organization or Veterans Affairs medical centers. We excluded multi-institutional studies in which such an obvious source of shared culture was not present and reports from state or multisite cancer

registries in which treatment was not directly observed.

Hazard of Death for Blacks and Whites

Two methods were required to calculate the hazard of death, each based on the assumption that survival-time distributions in the studies could be approximated by the exponential form $S(t)=e^{-\lambda t}$ (λ is the hazard; $S(t)$ is the probability of surviving beyond time t).[38] In circumstances where the survival curves or statistics were comparable in terms of treatments received and stage of disease, we anchored the reported actuarial survival for each group at a landmark time point—5 years unless the authors identified alternatives as more representative—and solved for λ in the preceding equation.[44] If only the median (m) was reported in these situations, the hazard was calculated using $\lambda = \log(2)/m$.

If the black and white cohorts were not comparable in terms of treatment, stage, or other relevant factors but a covariate-adjusted HR was reported, we derived the 2 hazards as follows. First, the hazard for whites was calculated using the reported actuarial estimate via the preceding equation. The hazard for blacks was then computed as the product of the covariate-adjusted HR × the hazard for whites.

Correction of Hazards for Differences in Population Mortality

For each cohort, from the overall hazard of death we subtracted the age, sex, and race appropriate hazard of death due to population mortality to determine the cancer-specific hazard of death. We determined population mortality rates from the National Center for Health Statistics 1997 decennial life tables, from which we subtracted death rates due to the cancer under study to avoid double counting.[45] The National Center for Health Statistics tables contain population estimates of annual death hazards (presented as probabilities) by race, sex, and age. The cancer hazards in the population were gleaned from the National Cancer Institute's 1994-1998 Surveillance, Epidemiology, and End Results (SEER) report, which classifies them similarly.[46] The hazard of population mortality for each racial group was taken to be the average of the hazards for each year of the study for a population matched to the race, sex distribution, and mean age of the cohort. When race-specific sex or age distributions were unavailable, we assumed that they were equal between the 2 groups.

SE of Hazard Ratios

For the majority of studies we determined the SE of the HR either based on the reported number of failures or by converting reported confidence intervals (CIs) using established methods.[38,44,47] In 23 (26%) of the cohorts, the data needed for these calculations were unavailable; therefore, we imputed an upper bound for the SE. This upper bound was calculated based on the assumption that exactly half of the total expected deaths at the landmark time point had contributed to the statistical power of the study, thus mirroring an analysis that would have been conducted if accrual were at a constant rate and the authors had analyzed the results when the first patient accrued had been followed up to the landmark (eg, the analysis occurred 5 years after the start of a study using a 5-year landmark). In reality, the results of most of these studies were likely analyzed at some later time point (after more failures) and so most estimates were probably associated with a smaller SE. Our assumption mitigates the influence of these cohorts on our overall pooled estimates, which is appropriate given our overall objectives. It was also assumed that the correction for other causes of death did not alter the SE of the log HR, because correction for population-based rates introduces virtually no additional random error.

Combination of Study Results Through Meta-analysis

For the meta-analyses, we used random effects models; our primary analysis was across all studies and our secondary analyses were by study grade and cancer type.[48] We assessed heterogeneity of the pooled HRs with the Q statistic.[48] We evaluated publication bias with a funnel plot and stratified and unstratified rank correlation tests.[49,50] We conducted the meta-analyses using Stata version 7.0 (Statacorp, College Station, Tex). All P values were 2-sided and values less than .05 were considered significant.

RESULTS

Systematic Review of the Literature

Evaluation of the 891 citations yielded 157 full-text articles. A search of the reference lists of those articles yielded an additional 19 studies. From these articles, we identified 89 unique analyzable cohorts reported in 54 articles that met our inclusion criteria. In aggregate, these cohorts reported on the survival of 32004 black patients (median, 108 patients per study) and 189877 white patients (median, 467 patients per study) with cancer of 14 different organ sites (TABLE).

Survival of Blacks and Whites After a Cancer Diagnosis

Across the 89 cohorts (FIGURE 1), blacks who received comparable treatment for similar stage cancer were at a 16% increased risk of death relative to whites (pooled HR, 1.16; 95% CI, 1.12-1.20; $P<.001$). After correction for differences in population mortality, the hazard of death was reduced to 1.07 (95% CI, 1.02-1.13; $P=.01$). The maximum influence on either of these estimates due to any particular cohort was 0.01, which we established by repeating our analyses removing 1 cohort at a time. These 2 results were robust across study grade, without evidence of heterogeneity.

In FIGURE 2, we present the results for overall survival and cancer-specific survival for particular cancer types, juxtaposed against the estimated proportion of cancer deaths due to each type in the black population.[97] For each of the 4 most common cancers (lung, colorectal, prostate, and breast, which collectively account for roughly half of all cancer deaths), blacks

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Table. Cohorts Analyzed in a Meta-analysis of Survival for Black and White Patients With Cancer, Stratified by Cancer Type and Comparability of Treatment*

		Study Grade							
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Cancer Site	Total No. of Cohorts	Source, y	No. of Cohorts	Source, y	No. of Cohorts	Source, y	No. of Cohorts	Source, y	No. of Cohorts
Lung	6	Akerley et al,[51] 1993	2	Bach et al,[28] 1999	1	Greenwald et al,[53] 1998	1	Page and Kuntz,[54] 1980	1
		Graham et al,[52] 1992	1						
Colorectal	11	Dignam et al,[29] 1999	5	...		Dominitz et al,[27] 1998	1	Manne et al,[41] 2000	1
		Akerley et al,[51] 1993	1			Mayberry et al,[55] 1995	1	Page and Kuntz,[54] 1980	2
Prostate	30	Thompson et al,[56] 2001	1	Hart et al,[60] 1998	1	Fowler et al,[39] 2000	1	Robbins et al,[67] 1998	3
		McLeod et al,[57] 1999	2	Kim et al,[61] 1995	2	Krongrad et al,[65] 1996	1	Fowler and Terrell,[40] 1996	2
		Roach et al,[58] 1992	3	Lawton et al,[62] 1994	2	Optenberg et al,[66] 1995‡	3	Powell et al,[68] 1995	1
		Crawford et al,[59] 1990	1	Austin and Convery,[63] 1993	1			Brawn et al,[69] 1993‡	4
				Zagars et al,[64] 1998†	1			Page and Kuntz,[54] 1980	1
Breast	21	Dignam et al,[70] 1997	2	Heimann et al,[72] 1997	1	Howard et al,[74] 1998	1	Mancino et al,[79] 2001	3
		Kimmick et al,[71] 1991	1	Fields et al,[73] 1989	1	Franzini et al,[75] 1997	1	Yood et al,[80] 1999	1
						Perkins et al,[76] 1996	1	Wojcik et al,[81] 1998	4
						Eley et al,[7] 1994	1	Ansell et al,[82] 1993	1
						Pierce et al,[77] 1992	1	Gregorio et al,[83] 1983	1
						Roetzheim et al,[78] 2000	1		
Gastric	1	...		...		...		Page and Kuntz,[54] 1980	1
Esophageal	1	...		Amendola et al,[84] 1980	1	...		...	
Leukemia	2	...		...		...		Page and Kuntz,[54] 1980	2
Multiple myeloma	2	Modiano et al,[85] 1996	1	Savage et al,[86] 1984	1	...		...	
Head and neck	5	...		...		Arbes et al,[87] 1999	1	Roach et al,[89] 1992	1
						Franco et al,[88] 1993	3		
Uterine corpus	2	...		...		Hill et al,[6] 1996	1	Hicks et al,[90] 1997	1
Central nervous system	1	Simpson et al,[91] 1996	1	...		...		...	
Bladder	1	...		...		...		Page and Kuntz,[54] 1980	1
Uterine cervix	5	...		Grigsby et al,[92] 2000	2	Howell et al,[93] 1999	1	Farley et al,[94] 2001	1
								Thoms et al,[95] 1995	1
Osteogenic sarcoma	1	...		...		...		Huvos et al,[96] 1983	1
Total No. of Cohorts	**89**		**21**		**14**		**20**		**34**
Total No. of Black Patients	**32 004**		**2341**		**2633**		**21 368**		**5662**
Total No. of White Patients	**189 877**		**17 156**		**15 472**		**129 576**		**27 673**

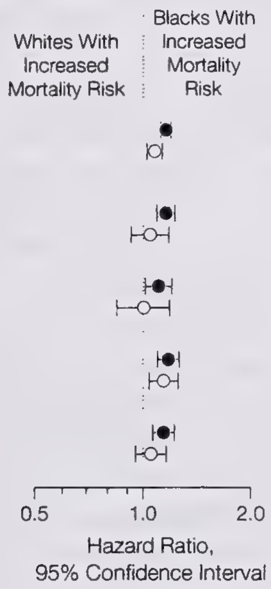
*Ellipses indicate no cohorts for that study grade. Study grades are detailed in the "Methods" section.

†This cohort was excluded from analyses corrected for population mortality because population mortality accounted for the entire hazard of death.

‡One of the cohorts from this study was excluded from analyses corrected for population mortality because population mortality accounted for the entire hazard of death.

Figure 1. Meta-analysis of the Hazard Ratio (HR) of Survival for Blacks Relative to Whites

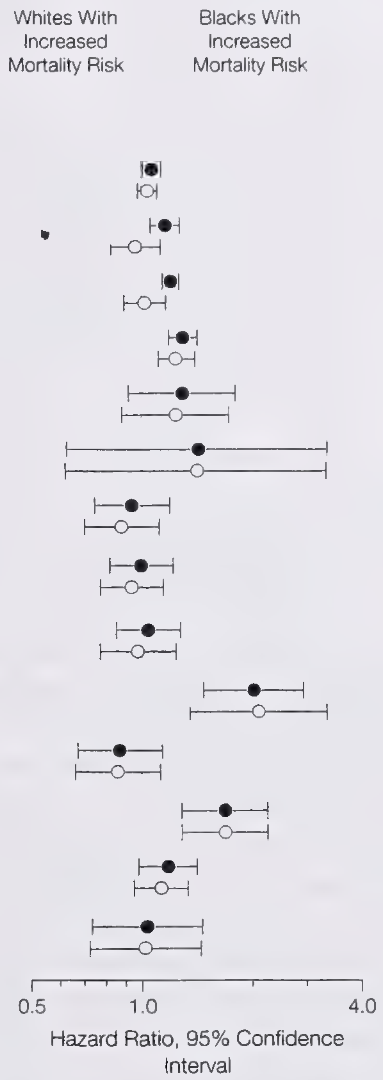
	No. of Cohorts: Overall Survival	No. of Cohorts: Cancer-Specific Survival
All	89	86
Study Grade		
1	21	21
2	14	13
3	20	19
4	34	33



The overall excess mortality was statistically significant ($P<.05$) for all cohorts combined and study grades 1, 3, and 4; excess mortality after correction for population mortality was statistically significant ($P<.05$) for all cohorts combined and study grade 3. The pooled overall HR is 1.16 (95% confidence interval [CI], 1.12-1.20; $P<.001$). The pooled cancer-specific HR is 1.07 (95% CI, 1.02-1.13; $P=.01$).

Figure 2. Meta-analysis of the Hazard Ratio (HR) of Survival for Blacks Relative to Whites for Particular Cancer Types

Type of Cancer	No. of Cohorts: Overall Survival	No. of Cohorts: Cancer-Specific Survival	Proportion of All Cancer Deaths in Blacks, %
Lung	6	6	26
Colorectal	11	11	11
Prostate	30	27	9
Breast	21	21	9
Gastric	1	1	4
Esophageal	1	1	3
Leukemia	2	2	3
Multiple Myeloma	2	2	3
Head and Neck	5	5	2
Uterine Corpus	2	2	2
Central Nervous System	1	1	1
Bladder	1	1	1
Uterine Cervix	5	5	1
Osteogenic Sarcoma	1	1	<1



The overall excess mortality was statistically significant ($P<.05$) for lung, colorectal, prostate, breast, uterine corpus, and bladder cancers; excess mortality after correction for population mortality was statistically significant ($P<.05$) for breast, uterine corpus, and bladder cancers. Numbers do not sum to 100 because all cancers are not represented.

were at a significantly excess risk of death overall. However, after correction for population mortality, there was no statistical evidence of excess cancer-specific mortality in blacks with the first 3 cancer types; the excess mortality in blacks with breast cancer was only moderately reduced (HR, 1.22; 95% CI, 1.10-1.37; $P<.001$).

For each of the remaining cancer sites, the results are based on either single studies or aggregation of very few studies. For the majority, cancer-specific mortality appeared similar for the 2 racial groups. The exceptions were the doubling of risk for blacks with cancer of the uterine corpus (HR, 2.08; 95% CI, 1.34-3.21; $P=.001$) and the 70% increased risk of mortality for blacks with cancer of the bladder (HR, 1.68; 95% CI, 1.28-2.21; $P<.001$). The pooled cancer-specific HR for all cancers other than breast, uterine, and bladder was 1.02 (95% CI, 0.97-1.06; $P=.49$), without evidence of heterogeneity (Q, 8.21; $P=.61$).

Tests for Publication Bias

We found no evidence of publication bias. We graphed the overall log HR for each cohort against its SE to form a funnel plot (FIGURE 3). In this figure, there is no systematic drift in the reported HR in relation to the SE of the study, constituting evidence against the hypothesis of publication bias. Statistical tests for detecting publication bias were also negative overall ($P=.45$), stratified by grade of study ($P=.79$), and stratified into studies of breast, uterine, or bladder cancer compared with other cancers ($P=.40$).

COMMENT

Disparities in treatment, rates of death due to other causes, and biological behavior of the cancer itself might each account for discrepancies in survival between blacks and whites with similar-stage cancer. We identified studies relevant to the bulk of cancer types and found that across these studies blacks were at a 16% increased risk of death. We then corrected this estimate for differences in underlying death rates and found that the pooled estimate of excess cancer-specific mortality for blacks was only 7%.

The excess cancer-specific mortality that was observed appeared to be due to a modest increase in risk of death for blacks with breast cancer (9% of cancer deaths in blacks), a doubling of risk for blacks with uterine cancer (2%), and a 70% increase in risk for blacks with

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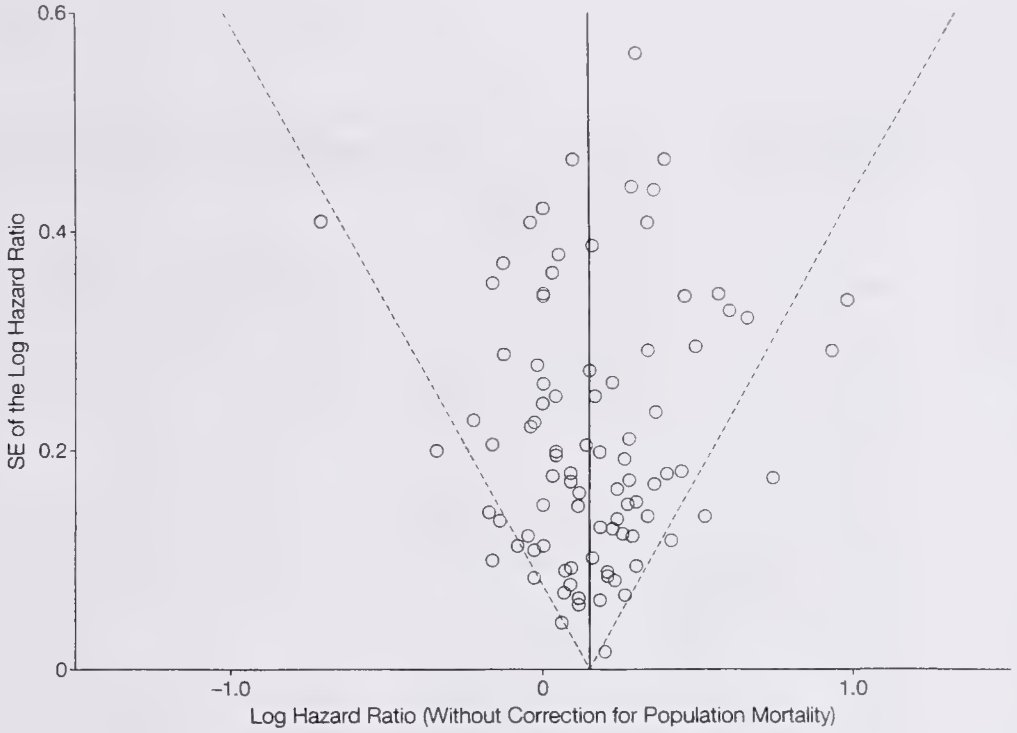
Figure 3. Assessed Publication Bias



The solid line represents the pooled estimate for the uncorrected log of the hazard ratio of 0.15; the dashed lines represent 95% confidence intervals around that estimate given the SE of the study.

bladder cancer (1%). In contrast, there were no appreciable differences in cancer-specific survival in lung cancer (26%), colorectal cancer (11%), prostate cancer (9%), and 8 other cancers assessed in this study.

These findings should be considered in the context of the data on which they are based. Our search did not yield information on all types of cancer nor did our rules for categorizing treatment ensure that the cohorts received care of similar quality. In determining cancer severity, cancer stage either within strata or based on covariate adjustment was available in all studies but further detail on clinically important prognostic factors was absent. We also lacked information on either the mode of cancer detection (eg, screen detected vs symptom detected) or the types of staging evaluations undergone by these cohorts. In general, disparities between blacks and whites in these latter parameters tend to increase the survival of whites relative to blacks—the first through lead time and length time biases,[98] the second through stage migration.[99] Conceivably, the survival differences that were observed between blacks and whites with breast cancer (Figure 2), for example, reflected the impact of cancer being detected more often through screening mammography in whites (and thus earlier in its natural history) than in blacks.[100-102]

There are quantitative limitations as well. We modelled survival using mathematical models that likely do not mirror the observed relations precisely. We corrected for population mortality based on rates of death matched for age, sex, and race from the National Center for Health Statistics and the National Cancer Institute's 1994-1998 Surveillance, Epidemiology, and End Results; in fact, in these cohorts the actual rates of death due to other causes may be different. In studies set in relatively homogenous populations such as Veterans Affairs medical centers, the rates for blacks and whites may be more similar than they are in the United States as a whole. A parallel concern is that particular groups of patients with cancer, such as those with lung cancer, have a greater comorbid disease burden than the average population. Although this phenomenon will increase rates of death due to causes other than cancer, it may attenuate the differences in underlying death rates between blacks and whites.[103]

Our methods, therefore, may have introduced measurement inaccuracies such that our reported CIs and accompanying *P* values do not capture the full degree of statistical uncertainty. The finding that differences in rates of death due to other causes reduced the HR for blacks relative to whites from 1.16 to 1.07 and eliminated the excess risk of mortality for blacks with colorectal, lung, and prostate cancer should be viewed in this context.

Finally, whether differences in death rates due to causes other than cancer constitute evidence of biological differences between blacks and whites was not addressed in this study. The death rates that were used in our calculations were derived from population statistics, which reflect the aggregate impact of differences in prevalence, severity, access to care, and, if present, biological differences. That there has been abundant documentation of disparities in care between blacks and whites for conditions such as heart disease and end-stage renal disease provides evidence that differences in treatment may be at least partially responsible for these disparities as well.[104] Similarly, this study focuses on subjects with a cancer diagnosis and therefore provides no insight into the extent to which biological differences may play a role in explaining racial differences in incidence rates, such as are seen in prostate cancer, gastric cancer, and uterine cancer.

Many researchers and physicians have concluded that poorer survival of blacks relative to whites after a cancer diagnosis reflects fundamental differences in the biology of the host or the attendant cancer or both. We did not observe the impact of these putative biological differences consistently in cohorts of comparably treated black and white patients with cancer of similar stage once we took into account differences in un-

derlying death rates. We cannot be sure if our findings in breast cancer, uterine cancer, and bladder cancer constitute exceptions to this conclusion or reflect residual differences in treatment and disease severity that could not be identified through our study.

These findings suggest that if biological differences do exist, they are responsible for at most a very small fraction of all cancer deaths. Therefore, biological differences between blacks and whites cannot explain a meaningful share of the racial disparity in cancer survival observed in the United States. Numerous studies have demonstrated that blacks are less likely to receive optimal care for cancer than whites and are also more likely to be diagnosed initially at an advanced stage of disease. Finding workable remedies for these latter inequalities, as well as addressing the control of comorbid diseases, are important public health goals and should be an objective of future research.

Author Affiliations: Health Outcomes Research Group, Department of Epidemiology and Biostatistics (Drs Bach, Schrag, and Begg and Ms Yakren) and Department of Medicine (Drs Bach and Schrag), Memorial Sloan-Kettering Cancer Center, and Weill Medical College of Cornell University (Mr Galaznik), New York, NY; and Winship Cancer Institute, Emory University, Atlanta, Ga (Dr Brawley).

Author Contributions: *Study concept and design:* Bach, Schrag, Brawley, Begg.
Acquisition of data: Bach, Galaznik, Yakren.
Analysis and interpretation of data: Bach, Schrag, Galaznik, Yakren, Begg.
Drafting of the manuscript: Bach, Schrag, Galaznik, Begg.
Critical revision of the manuscript for important intellectual content: Bach, Schrag, Brawley, Yakren, Begg.
Statistical expertise: Bach, Schrag, Begg.
Obtained funding: Bach.
Administrative, technical, or material support: Bach, Brawley, Galaznik, Yakren, Begg.
Study supervision: Begg.

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April 24, 2002

Racial Gap in Cancer Survival Is Not Biological, Study Finds

BY REUTERS

CHICAGO, April 23 — A study published today cast doubt on speculation that biological or genetic differences cause cancers to spread more aggressively in blacks than whites, leading to lower cancer survival rates.

More likely, the report from Memorial Sloan-Kettering Cancer Center in New York concluded, the well-documented disparity in survival rates between the races is caused by other factors, including coexisting medical conditions.

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In the United States, 63 percent of white cancer patients survive after five years, compared with 52 percent of blacks. Income, insurance coverage, general health and time of diagnosis are all thought to play a part in that disparity.

Blacks suffer disproportionately from problems like diabetes and heart disease, studies have shown.

The study, published today in The Journal of the American Medical Association, was based on a review of all English language studies comparing survival for black and white cancer patients published from 1996 to January 2002. It covered 189,877 white and 32,004 black patients.

It found that in cases where black and white cancer patients received equal treatment — comparable care at a similar stage of the disease — blacks still had a slight survival disadvantage. But once deaths from all

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other health conditions were considered, cancer survival was basically the same, the report said.

"There is not much evidence that cancer behaves differently in blacks than in whites," said Dr. Colin Begg, chairman of the department of epidemiology and biostatistics at Memorial Sloan-Kettering. "Differences in treatment, stage of disease at presentation and mortality from other diseases — not biological or genetic differences — seem to explain most of the disparity."

Dr. Begg added, "These are the areas that should be the primary targets for future research and public health interventions."

The study did find that blacks were at a significantly higher risk of death from three types of cancer: breast cancer and two relatively rare cancers, uterine and bladder. There was no appreciable difference in death rates from lung, colorectal, prostate and eight other cancers assessed in the study.

"These findings suggest that if biological differences do exist, they are responsible for at most a very small fraction of all cancer deaths," the report concluded.

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Addressing Racial And Ethnic Barriers To Effective Health Care: The Need For Better Data

Health plans can play a critical role in eliminating health disparities by developing viable data collection strategies—and using them.

by Arlene S. Bierman, Nicole Lurie, Karen Scott Collins, and John M. Eisenberg

PROLOGUE: Improving the quality of care all Americans receive will require the elimination of racial and ethnic disparities in health. And making progress against disparities will require the collection of reliable data on race and ethnicity. Private managed care organizations enroll many persons whose care is financed by federal and state governments. This paper's four authors, all of whom are physicians, make the case that health plans can make a valuable contribution toward eliminating racial and ethnic disparities in health by collecting and using these data for quality improvement. The authors acknowledge that the issue is not without controversy and underscore the need for consensus building among patients, providers, insurers, and public and private purchasers on how to best achieve this objective. Barriers to data collection and strategies to overcome them are discussed.

Arlene Bierman is a general internist, geriatrician, and health services researcher who joined the Agency for Healthcare Research and Quality (AHRQ) in 1997. She is senior research physician in AHRQ's Center for Outcomes and Effectiveness Research. She received her medical degree from the University of North Carolina, where she was a Morehead Fellow; she also holds a master's degree in clinical evaluative sciences from Dartmouth. Nicole Lurie, Alcoa Professor of Health Policy Analysis at RAND, served as the principal deputy assistant secretary of health in the Department of Health and Human Services from 1998 to 2001. She attended medical school at the University of Pennsylvania and holds a master of science in public health from the University of California, Los Angeles. Karen Scott Collins is responsible for developing the Commonwealth Fund's program on Quality of Care for Underserved Populations, with a focus on minority and low-income populations. She earned her medical degree from Cornell University Medical College and holds a master of public health degree from the Johns Hopkins Bloomberg School of Public Health in Baltimore. John Eisenberg had been director of AHRQ since 1997 until his untimely death 10 March 2002. He received his medical degree from Washington University in St. Louis and a master of business administration degree from the Wharton School, University of Pennsylvania.

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ABSTRACT: Racial and ethnic disparities in health outcomes and quality of care have been observed among persons with similar health insurance, within the same system of care, and within the same health plan. National efforts to eliminate these disparities are hindered by the lack of race/ethnicity data. Collection of these data by health care providers, coupled with standards for collection, use, and privacy protection, would be a first step toward eliminating disparities. Although no national consensus exists with respect to data collection, the weight of prior research, related public and private efforts, and growing diversity of the U.S. population are likely to increase demand for accurate data on race and ethnicity in health care settings.

Elimination of racial and ethnic disparities in health has emerged as a central challenge for health care delivery in the United States. While the causes of health disparities are multifactorial, differences in access to care, use of services, health care quality, and physician-patient communication have all been shown to contribute.[1] Racial and ethnic disparities in health outcomes have been observed among persons with similar health insurance, within the same system of care, and within the same managed care plan.[2] Although targeted interventions have narrowed and even closed some of these gaps, others persist.[3] Research into the underlying factors contributing to health disparities and the design, implementation, and evaluation of interventions to eliminate them is needed. These efforts have been hindered by the general lack of standardized data on race and ethnicity in health care settings, because without these data, disparities cannot be assessed.

As major purchasers of health care, federal and state governments can play a vital role in eliminating health disparities. However, before progress can be made, public and private stakeholders (purchasers, providers, and the public) must address multiple barriers to data collection. Because many Americans, including beneficiaries of publicly funded programs, are enrolled in managed care, health plans can play a critical role in supporting efforts to eliminate disparities and in developing viable strategies to collect race/ethnicity data for this purpose.

To promote dialogue on these issues, components of the U.S. Department of Health and Human Services (HHS) and the Commonwealth Fund cosponsored a meeting in June 1999 to bring together representatives of managed care, purchasers, and federal agencies.[4] We report on this dialogue and provide an overview of issues related to the use, collection, and interpretation of race/ethnicity data in managed care. To reflect ongoing discussions, we draw on information from multiple primary sources and discussions in other forums among the provider, purchaser, governmental, and health services communities to describe selected activities by managed care plans to collect and use race/ethnicity data, and to identify barriers to data collection and potential strategies to overcome them.

Uses And Collection Of Race/Ethnicity Data

■ **Uses of data.** As the United States grows more diverse, health plans have an

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interest in improving health outcomes and patient satisfaction among diverse enrollee groups. Managed care plans can use race/ethnicity data on their enrollees to (1) inform program development, planning, and priority setting; (2) target quality improvement efforts; (3) understand differences in performance within a plan; (4) understand the health needs of specific populations and develop appropriate interventions; (5) identify the need for and deploy resources for the provision of culturally and linguistically appropriate services; and (6) evaluate and monitor the effectiveness of interventions.

Public and private purchasers can use data on care provided to various racial and ethnic groups to compare health plans and to choose plans that provide the best-quality care. Employers can use such information to assure that different segments of their workforce are receiving care of equivalent quality. This information can also help to inform individual decisions about health plan choice. Policymakers can use such data to develop policy and program strategies. These data can provide researchers with the evidence base to inform all of these activities.

■ **Examples from the private and public sectors.** Although managed care plans have not routinely collected data on race and ethnicity, they have developed a variety of strategies for obtaining these data for specific projects. Some plans view the examination of clinical performance in selected domains for various population subgroups as a logical component of quality improvement programs. Because there is no current inventory of health plans' initiatives to address health disparities, we provide some illustrative examples of leadership by both the private and public sectors in this area.

Some health plans, including Prudential's Center for Health Care Research and UnitedHealth Group, collect race/ethnicity data for specific quality improvement efforts.[5] Aetna U.S. Healthcare has determined that strategies regarding both market share and the provision of high-quality care require knowledge of enrollees' race and ethnicity.[6] Aetna therefore has developed a set of Minority Health Initiatives, one of which focuses on collecting race/ethnicity data to increase capacity to study disparities in access and health status and to facilitate the development and implementation of culturally appropriate outreach and intervention programs. Resources have been allocated for the voluntary collection of data on new enrollees' race/ethnicity and language preference.[7]

In the Quality Assessment and Performance Improvement requirements for 2003 under the Quality Improvement System for Managed Care (QISMC), the Centers for Medicare and Medicaid Services (CMS) requires Medicare+Choice (M+C) plans to conduct a quality improvement project that addresses either clinical health care disparities or culturally and linguistically appropriate services.[8] The Veterans Health Administration (VHA), comparable to a large health plan, has collected race/ethnicity data together with assessment of health and functional status, using a well-validated instrument adapted for veteran populations, the SF-36 VA. The VHA thus has the capacity to assess differences in health status

by race and ethnicity for quality improvement.

Approaches to data collection. Lacking a uniform data collection infrastructure, health plans use a variety of strategies to collect race/ethnicity data: electronic medical records, administrative data, enrollee surveys, data linkages, and federal and state enrollment files for Medicare and Medicaid beneficiaries, respectively.

Medical records. Some Harvard Pilgrim practices collect race and ethnicity data in their electronic medical records. However, missing data remain a challenge for several reasons: Not all providers use these electronic medical records or record race and ethnicity in the available field; data are available only for those enrollees using services; and data are reported by the clinician rather than by the enrollee. An alternative approach used by Kaiser Permanente Northern California and Harvard Pilgrim is collection of data on language preference when an appointment is made or during enrollment.

Data linkages. Several managed care organizations are working in partnership with the Commonwealth of Massachusetts to obtain race/ethnicity data by adding health plan identifiers to state databases such as birth certificates and tumor registries. Such data can then be linked to other databases. For example, information from state hospital discharge data linked to birth certificate information has provided data on low birthweight by race and health plan, as well as stratified and risk-adjusted data for cesarean sections. Massachusetts, in partnership with health plans, also asked respondents to identify the source of their health care coverage on the Behavioral Risk Factor Surveillance Survey (BRFSS) sponsored by the Centers for Disease Control and Prevention (CDC). The intent is to make health plan-specific information on enrollees' risk behavior and prevention practices available by race and ethnicity. Because the survey is representative of the state population, comparisons between managed care and fee-for-service (FFS), as well as between insured and uninsured persons, may be possible.[9]

State Medicaid data. The CMS collects statistics from state Medicaid programs on the race and ethnicity of beneficiaries. However, there is considerable state variation in the completeness and reliability of these data. The availability of data to health plans also varies by state.[10] Representatives from Harvard Pilgrim Health Plan (Massachusetts) and Access Health Systems (Tennessee) reported receiving race/ethnicity data from their state Medicaid programs.[11] A Minnesota health plan, Medica, examined quality of care for different conditions for different racial and ethnic groups using data on race and ethnicity from its state Medicaid program. Disparities in quality were present in some areas but not in others. Medica is taking steps to understand and address identified disparities.[12] Also, proposed rules for Medicaid managed care require states to collect data on beneficiaries' race, ethnicity, and primary language and to make these data available to plans.[13]

Geocoding. Another approach used to examine differences in performance for different enrolled populations in the absence of person-level data is small-area analysis using area-level data, conducted by geocoding. Geocoding is a method to ob-

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tain sociodemographic characteristics about the neighborhood in which a person lives via linkages to census data. Census data can provide information on the household income, education, occupation, and race/ethnicity of residents of a given area. For example, the New York Hospital Community Health Plan studied the rate of hospital admissions for asthma according to the asthmatics' neighborhoods of residence and designed interventions to improve asthma care based on the geographic distribution of asthma prevalence. Area-level census data have been used to assess variations in plan performance by race/ethnicity and socioeconomic status.[14] This method is better for assessing socioeconomic status than for race/ethnicity, since the utility of census-derived measures as a proxy for race or ethnicity varies by the level of neighborhood integration.[15]

Multiple data sources. The CMS allows M+C plans to choose among several sources of race/ethnicity data for quality improvement projects under QISMC. These include primary data collection by plans at the time of or subsequent to enrollment, data from the CMS enrollment database (EDB), area-level data, and survey data on race and ethnicity obtained through the Consumer Assessment of Health Plans (CAHPS).[16] The data in the EDB are supplied by the Social Security Administration. Studies have found that the EDB has a 97 percent sensitivity for identifying white and black persons but a sensitivity of less than 60 percent for other racial/ethnic groups including Hispanics, Asians, and Native Americans.[17] Procedures are in place to increase the reliability of these data over time.

Barriers To Data Collection And Use

Perceived barriers to the routine collection of race/ethnicity data include data quality, legal issues, and concerns about confidentiality and privacy, potential for misuse, public reporting, and cost. Plans reported at our June 1999 meeting that they generally do not perceive demand for these data by payers and regulators but acknowledged that there are many potential sources of demand in the near future as awareness of and commitment to eliminating health disparities grow in the private and public sectors.

■ **The business case.** Most plans did not feel that the business case for the collection of these data had been made and that this presents a major barrier to data collection. However, some plans have concluded that improving quality for all enrollees may serve to maintain or increase market share.[18] It has been argued that use of these data could provide market advantage and even reduce costs. For example, improving publicly reported Health Plan Employer Data and Information Set (HEDIS) measures by targeting enrollee groups with poor performance, or reducing costs through better clinical management, could create a fiscal benefit. The business case could be created through the use of financial and other incentives, but there is no consensus in the policy community on whether or how to do this. The business case developed by HHS for inclusion of race and ethnicity as a data element under the 1996 Health Insurance Portability and Accountability Act (HIPAA) may serve as

a model. A December 2001 conference sponsored by the National Institutes of Health (NIH) aimed at better articulating the business case for data collection, evidence that research and policy communities are cognizant of the need for this business case and that momentum is building toward its development.

■ **Improving data quality.** Use of existing federal standards, coupled with the application of lessons learned from the collection and use of these data in other health care settings, can inform efforts to improve the availability, quality, and comparability of these data in managed care. For example, twenty-nine of forty-four states that collect hospital discharge data also collect race and ethnicity data.[19] Studies using state hospital databases have found racial and ethnic differences in the use of diagnostic and therapeutic procedures.[20] State hospital discharge data are limited in that misclassification errors can result when observer identification (rather than self-identification) is used and that data elements are not standardized across states. Studies have shown that the frequency of misclassification errors from observer identification varies by race and ethnicity. The Massachusetts Health Data Consortium compared assignment of race and ethnicity in its hospital discharge abstract database with the self-reported race of mothers in birth certificate data. The consortium found 97 percent agreement for whites, 93 percent agreement for blacks, and 91 percent agreement for Hispanics.[21] The National Center for Health Statistics (NCHS) conducted a study on the quality and reliability of death rates by race and Hispanic origin in official U.S. mortality statistics and found greater than 98 percent agreement between recorded and self-reported data for blacks and whites, 89.7 percent for Hispanics, and 57 percent for Native Americans.[22]

Use of a standard classification scheme, such as those developed by the Office of Management and Budget (OMB), would permit comparisons across different settings, systems of care, and geographic areas.[23] These standards recognize that data categories that go beyond minimum standards and reflect the diversity of enrolled populations may be needed to target interventions.[24] For example, a plan might need to distinguish among subgroups of Latinos, blacks, Asians, and Native Americans. The development of a standard classification system with standard category definitions that allows comparison of subgroups across data sources would facilitate these efforts. The ability to aggregate these sometimes small subcategories back into the standard classifications is needed for developing a national profile, for public health reporting, and for conducting comparative analyses.

■ **Interpretation of race and ethnicity data.** The use of additional data elements can foster appropriate data interpretation. To understand the role of race and ethnicity in context, other relevant factors such as socioeconomic status, language preference, acculturation, health literacy, and neighborhood characteristics need to be considered. An understanding of the independent contribution of these nonclinical determinants of health to health disparities and their interaction with race and ethnicity can facilitate quality measurement and help to guide the development of effective interventions.[25]

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■ **Perceived legal barriers.** A common misperception among health plans is that federal law prohibits the routine collection of data on their enrollees' race and ethnicity. According to the HHS Office for Civil Rights, there is no such federal prohibition.[26] A review of state laws and regulations regarding the collection of race/ethnicity data by health insurers found that forty-six states and the District of Columbia place no restrictions on data collection. Among the four states where restrictions were identified, differences exist as to whether the restrictions apply before, during, or after enrollment. One state even requires health maintenance organizations (HMOs) to collect and report data on race and ethnicity.[27]

Federal inclusion policies for the collection of race/ethnicity data mandate the collection of such data in HHS-sponsored and -maintained data collection activities.[28] Discussions underscore that voluntary disclosure and self-identification by enrollees are preferable. Techniques for collecting sensitive information, such as explaining what the data will be used for and providing procedural safeguards, are recommended.[29]

■ **Privacy and confidentiality concerns.** Privacy of health information is a major consideration. An Institute of Medicine (IOM) report discusses how proposed and current efforts to protect the confidentiality of medical records could help to provide protection against misuse.[30] New standards for electronic data transmission under HIPAA include race/ethnicity as an optional data element for hospital discharge data.[31] Scheduled for mandatory compliance effective 14 April 2003, the HHS Privacy Rule will protect the confidentiality of individually identifiable health information when held by health plans, clearinghouses, and providers who use specified electronic transactions.[32] This rule does not preclude the collection of race/ethnicity data, and, in fact, its provisions can serve to protect confidentiality.

There is evidence that individuals are willing to provide this information when clear explanations of its use are provided. For example, the Henry Ford Health System encountered a favorable response from community leaders in efforts to collect these data, as long as data were used for improvement purposes and collected by self-identification.[33]

■ **Concerns about the misuse of race/ethnicity data.** The potential for misuse of data on race and ethnicity is a concern. Enrollees might be fearful that a health plan could use this information to deny or drop coverage or to charge higher rates. Clear guidelines for the use of these data will need to be established, as will the consequences for violating them. Education for health plans and consumers about the value of data collection and the advantages that can be derived from data use can help to address these concerns.[34]

■ **Timing of data collection.** One strategy used to limit the potential for misuse

is to collect race/ethnicity data after enrollment, such as at the time of an initial health assessment. Plan representatives remarked that the costs of collecting data at enrollment are lower than the costs for data collection after enrollment. Some states have developed strategies to collect data at enrollment to guard against discriminatory enrollment decisions. For example, independent brokers may be used to enroll beneficiaries into Medicaid managed care. One state uses a separate tear sheet from the application to collect data at the time of enrollment.[35]

■ **Concerns about public reporting and accountability.** Performance measurement is used for three distinct but related activities: quality improvement, public reporting to inform purchasers' and consumers' choices, and accountability through accreditation processes. While the value of using race/ethnicity data for quality improvement is recognized, there is far less consensus about public reporting because of concerns that only some of the observed disparities would be within health plans' control. Plans stressed the need to include FFS health care in comparable performance measurement efforts.

■ **Costs of data collection.** Cost remains an important barrier to data collection. More information is needed as to what the actual costs of data collection are, as well as how to minimize them. Standardized and routine collection may reduce these costs. These data are routinely collected in other sectors: housing, education, and employment for civil rights enforcement.[36] Examination of these sectors may be able to provide critical information to the health sector about costs and their allocation. Further dialogue among policymakers, providers, and purchasers is needed on how to distribute the cost burden.

Related Activities

There has been substantial activity in both the public and private sectors aimed at addressing health disparities, including calls for data collection, heightening awareness of the problem and contributing to future demand for data. AHRQ's 1999 reauthorization requires the agency to develop annual reports to the nation on trends in health care disparities beginning in 2003. This report will be enhanced by the availability and use of race/ethnicity data to develop and report performance measures. At a recent meeting of AHRQ's Integrated Service Delivery Research Network, which included managed care representatives, the need to disseminate information to policymakers about the use and collection of race/ethnicity data was identified as a priority. The National Committee on Vital and Health Statistics recommended the collection of uniform enrollment data, including race and ethnicity, along with other demographic factors during enrollment in Medicaid managed care.[37] The State Children's Health Insurance Program (SCHIP) requires states to collect and report data on the race, ethnicity, and primary language of enrolled children.[38] The Minority Health and Health Disparities Research and Education Act of 2000 requests an IOM report describing the data needed to support efforts to evaluate the effects of race and ethnicity on access to

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and quality of health care. Two additional IOM committees are examining various aspects of the issues outlined here; these committees' reports may form a foundation for building consensus.[39]

There has been growing recognition in the private sector about the value of using race/ethnicity data for quality improvement. For example, the American Association of Health Plans (AAHP) developed a bimonthly insert to its newsletter called "Disparities in Care," which has included features on the importance of the collection and use of data on race and ethnicity. The Commonwealth Fund has supported the development of Minority Health Report Cards, a National Quality Forum workshop on quality measurement and disparities in care, and a comprehensive review of federal policies and practices related to data collection.[40]

Future Directions

The 2000 census has drawn attention to the growing racial and ethnic diversity of the U.S. population. At a time when the decoding of the human genome has confirmed evidence against the validity of race as a biological construct, race and ethnicity continue to be important social constructs correlated with access to and quality of care.[41] There is cause for optimism that effective interventions can have an impact. The IOM's recent report, *Crossing the Quality Chasm*, identifies equity as one of the six key quality dimensions on which our current health system falls short.[42] Citing the large body of literature on health disparities, the report states that health care should be equitable and that care should not vary in quality because of personal characteristics, including race.

We conclude with the following observations drawn from multiple discussions. First, quality improvement efforts aimed at eliminating racial and ethnic disparities in health are dependent upon the availability of reliable data on race and ethnicity. However, universal data collection will require the participation and collaboration of the federal government, state governments, and the private sector, including health plans and insurers, providers, purchasers, and consumers.

Second, the quality, usefulness, and acceptability of data may be enhanced through a number of mechanisms. Data collection standards that encourage use of expanded categories of race and ethnicity locally, which can be collapsed into the OMB reporting format to assess trends and carry out comparisons nationally, can provide the level of detail needed to improve quality at the local level while providing standardized data to assess national progress. The reporting of race/ethnicity data based upon self-identification is recognized as the more accurate method of data collection. Mechanisms to safeguard the confidentiality of these data as well as guidelines for appropriate use will need to be developed. Data collection that

includes information on related social factors, such as socioeconomic status and language spoken at home, will further enhance the ability to tailor quality improvement strategies and increase the likelihood of eliminating disparities in care.

Third, pilot projects to demonstrate these data's utility for quality improvement should be able to provide valuable information for future initiatives. Collecting and analyzing race/ethnicity data in ongoing quality improvement activities, such as the Diabetes Quality Improvement Project (DQIP), can expand the current knowledge base. Partnerships that include representation of diverse population groups and different systems of care in improvement interventions will foster the generalizability of the findings from these projects.

Fourth, education of the public, insurers, purchasers, and providers about the benefits and appropriate use of these data, and education for health care personnel on how to collect these data, can help to assure that the data will be used for public benefit. Finally, careful examination of both the community benefit and the business case for data collection will be needed to inform future decision making.

THE COLLECTION OF RACE/ETHNICITY DATA by health care providers, coupled with national standards for collection, use, and privacy protection, would be a first step toward eliminating health disparities. Nevertheless, there are multiple barriers and sources of resistance to data collection, and this remains a sensitive issue. Although there is no national consensus with respect to the collection of data on race/ethnicity for performance measurement in health care settings, the weight of prior research, the goals and needs of Healthy People 2010, related public and private efforts, and the demographic changes in the U.S. population are likely to increase the demand for such data in the years to come.

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level of antigen-presenting cells such as dendritic cells[10] and stimulates osteoclast-mediated bone resorption directly or indirectly by the receptor activator of nuclear factor-κB and its ligand.[11] Histologic studies of synovial-biopsy specimens from patients with spondyloarthropathies who were being treated with anti–TNF-α agents have shown reductions in the thickness of the synovial lining, vascularity, and cellular infiltration with neutrophils, macrophages, and T and B cells.[7,8] In contrast, the use of these agents in patients with rheumatoid arthritis is associated with decreased numbers of macrophages; alterations in lymphocyte infiltration are less striking.

In the study by Gorman et al., the marked changes that resulted from etanercept therapy were mostly subjective. They included decreases in stiffness and pain and improvement in overall function, along with objective findings such as an increase in chest expansion and a decrease in the erythrocyte sedimentation rate. As one would expect, there was little peripheral-joint involvement in the cohort, and one might wonder why it was deemed necessary to examine 66 joints without specifically mentioning sacroiliac joints. Because peripheral-joint involvement was minimal, the difference between the etanercept and placebo groups in the change from base-line scores for joint tenderness was not significant. There was no major change in scores for fatigue, whereas therapy with anti–TNF-α agents reduces fatigue in patients with rheumatoid arthritis[10]; these conflicting findings provide further evidence of differences between the disorders. As for side effects, there has to be concern about the possibility of neurologic complications in the light of reports of demyelinating disease in patients with other disorders who have been treated with etanercept.[12] Regrettably, only a few biologic abnormalities were assessed in the current study (the erythrocyte sedimentation rate and C-reactive protein), and the most sophisticated imaging methods were not used. In a smaller study of patients with spondyloarthropathy,[13] magnetic resonance imaging was very useful for assessing the response of lesions to treatment with etanercept. Such techniques may prove useful in assessing specific features of ankylosing spondylitis, such as periosteal reactions and ectopic ossification of ligaments. Improved biologic monitoring during the course of treatment with the same agent in patients with different immunoinflammatory diseases would lead to a better understanding of the pathogenesis of these disorders and would help identify the best markers of a treatment response. With all the new scientific tools available, a combined effort on the part of academic researchers and pharmaceutical companies is needed to identify the patients who are most likely to benefit from TNF-α inhibition, not only because of the cost of this treatment but also because of its possible long-term side effects.

JEAN-MICHEL DAYER, M.D.
Geneva University School of Medicine
1211 Geneva 14, Switzerland

STEPHEN M. KRANE, M.D.
Massachusetts General Hospital–East
Charlestown, MA 02129

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RACIAL DISPARITIES IN CLINICAL TRIALS

THE rational use of a new drug or treatment should be based on the results of controlled clinical trials that are well designed, avoid bias, and include subjects representing the full range of patients who are likely to receive the treatment once it is marketed. In addition to age, sex, diet, underlying disease, and the concomitant use of other medications, race and genetic factors may play pivotal parts

in the variability of subjects' responses to a medication.[1] Regrettably, minority groups are underrepresented in most clinical trials. Often, there are insufficient data to assess the effectiveness or safety of new drugs in members of minority groups, especially blacks. Concern about this issue led the National Institutes of Health[2] and the Food and Drug Administration[3] to establish guidelines encouraging the inclusion of more women and minority groups in clinical trials. However, it is uncertain whether these guidelines are being implemented and whether the participation of minority groups in clinical trials has increased.

In this issue of the *Journal,* Gifford and colleagues[4] report that an impressive 14 percent of adults receiving care for human immunodeficiency virus (HIV) infection in the United States participated in a clinical study between 1996 and 1998, and 24 percent received an experimental medication during that period. An additional 8 percent tried unsuccessfully to get experimental HIV treatments. Gifford et al. analyzed data from the HIV Cost and Services Utilization Study cohort — a reference population of 2864 persons who are representative of the 231,400 adults with known HIV infection who made at least one visit for regular health care (other than to an emergency department or a military or prison facility) in the 48 contiguous United States in early 1996. Factors associated with participation in a clinical trial of HIV treatment included non-Hispanic white race, male sex, a history of male homosexual contact, education beyond the high-school level, an annual income of more than $25,000, private fee-for-service health insurance, and residence within one mile of a center participating in such a trial. Non-Hispanic blacks and Hispanic persons were less likely to participate in trials than non-Hispanic whites. Of blacks who were enrolled in clinical trials at the start of the study, only 25 percent were enrolled in trials at follow-up, as compared with 53 percent of whites.

The report by Gifford et al. has important implications for the care of people with HIV infection and the representation of minority groups in clinical trials. Much of the improvement in outcomes for patients with HIV infection resulted from the widespread use, after 1996, of highly active antiretroviral therapy. Remarkably, by 1998, 90 percent of HIV-infected patients with private insurance and 79 percent of patients without health insurance had received such therapy.[5] Despite these encouraging data, Gifford and colleagues show that black race and Hispanic or "other" ethnic background negatively influenced access to clinical trials.[4] This disparity persisted in their study even for blacks who tried to get experimental medications.

Moreover, providers who were experienced in the treatment of HIV infection (and were therefore most likely to be involved in or to know about clinical trials) cared for most of the patients in this cohort. Thus, one inference might be that either overt prejudices or subconscious perceptions on the part of these physicians influenced access to HIV-related clinical trials. Because these data were generated in a nationally representative cohort of HIV-infected persons receiving regular medical care, the problem may be pervasive.

Why are minority groups underrepresented in clinical trials of treatments for HIV infection? There are barriers at the levels of the patient, the physician, the institution, and the community.[6-8] Although a complete discussion of these barriers is beyond the scope of this editorial, several key points can be made. Beliefs, behavior, attitudes, perceptions, and expectations influence both patients and physicians. Moreover, these factors may affect the patient–physician relationship in ways that neither party consciously perceives. Physicians need to recognize and accept the fact that despite their desire to view each patient objectively and to base decision making on biomedical information about that patient, it is often impossible to meet this goal.[9] Limited data suggest that health care providers, like the rest of society, harbor prejudicial attitudes (biases or stereotyping) toward minority groups — particularly blacks. Furthermore, these attitudes may influence a provider's decisions about treatment.[9,10] Patients often respond to such attitudes with mistrust of the physician and reluctance to comply with treatment.[9] This dynamic is particularly important in the informed-consent process (designed to inform patients of the risks and benefits associated with participation in a clinical trial and to facilitate self-determination), during which a lack of trust often leads to the patient's refusal to enter a clinical trial.[11] Many blacks view signing the informed-consent document as relinquishing their autonomy and providing legal protection for the physician or the institution.[11]

Breaches of trust on the part of the patient or the physician appear to be a major factor contributing to disparities in the care provided to members of racial and ethnic minority groups.[12] Health care workers who exhibit humane qualities (e.g., compassion, empathy, and honesty) and communicate in a respectful and culturally appropriate manner foster trust. Trust increases the patient's involvement in care, adherence to recommended treatment, and willingness to participate in research.

The failure of drugs due to viral resistance is a common and serious problem in antiretroviral therapy. The consistency of adherence to highly active antiretroviral therapy predicts the biologic outcomes for HIV-infected persons in clinical trials.[13] Pharma-

ceutical companies, as part of their efforts to obtain licensing approval, perform most trials of anti-HIV drugs. Consequently, researchers purposely avoid recruiting marginalized populations (such as members of minority groups, substance abusers, or homeless persons) to clinical trials because they believe that poor compliance is common in these groups. Many obstacles to participation by such patients (e.g., homelessness, lack of transportation, limited income, lack of child care, and active drug use) are probably surmountable and, more important, in many studies have not predicted poor compliance.[14] Many other factors are also related to adherence, including fluency in English, the level of functional health literacy (a measure of a patient's ability to read and comprehend written information and to perform numerical tasks related to health care),[15] the complexity of the medication regimen, and the efficacy of the regimen. In clinical practice, physicians have to assess each patient's understanding of the prescribed regimen or tailor the regimen to fit the lifestyle of the patient.[14] However, most clinical trials are not designed to deal with these issues, so the population involved in studies rarely mirrors the full spectrum of patients who are likely to receive the treatment. As a result, many trials of antiretroviral drugs do not provide information on how to use the medications in routine clinical practice.

Finally, investigators have a narrow view of the sort of person who makes a good participant in an HIV-related clinical trial: a white, college-educated, employed, housed, homosexual man. As a result, they have a more difficult time recruiting patients for such trials. In part, recruitment is difficult because many drugs are already available, combination therapy works, and the health of HIV-infected patients is improving. Many patients are reluctant to enroll in new trials, and their physicians, many of whom have a "let's wait and see" attitude, do little to encourage them. But the battle is far from over. The scientific and health care communities must continue aggressive efforts to educate patients with HIV infection about clinical trials and to motivate and encourage them to participate in such trials. In order to provide generalizable results, trials must involve men and women, both homosexual and heterosexual, of all racial and ethnic groups, irrespective of their financial circumstances.

TALMADGE E. KING, JR., M.D.
San Francisco General Hospital
San Francisco, CA 94110

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IRB REFORM

WE have come a long way since the 1960s, when ethical questions about research involving human subjects brought the issue to national attention. Nonetheless, the current system for safeguarding people who volunteer for clinical trials is under stress because of the unprecedented growth in clinical research.[1-3] Since 1995, federal funding for research has more than doubled. From 1997 to 2000, the estimated number of participants in federally funded research increased from 7 million to almost 12 million[4] (and Seto B: personal communication). Privately sponsored clinical research has grown at a similar pace.[5] To paraphrase Snyderman and Holmes, as our ability to discover expands, we must be ready for the increasingly dominant role of clinical research in medical practice.[6]

Two articles in this issue of the *Journal* examine current efforts to improve the system for reviewing research protocols. Christian et al. describe a central review process for multi-institutional studies that allows institutional review boards (IRBs) to focus on

DIVISION OF MEDICAL ASSISTANCE
TESTIMONY FOR THE JOINT COMMITTEE ON HEALTH CARE
ON RACIAL AND ETHNIC DISPARITIES IN HEALTH CARE
JUNE 4, 2002

Thank you for the opportunity to testify today before the Joint Committee on Health Care. The Division shares the legislature's concern and goal to identify policies and programs that may be directed toward eliminating the impact of race, ethnicity, language, gender and geographic location in the provision of quality health care. The Division has undertaken significant efforts and implemented policies towards reducing the impact of racial and ethnic disparities in the provision of health care since fiscal year 1996. Such efforts are part of the Division's mission to help the financially needy obtain high quality health care that is affordable, promotes independence and provides customer satisfaction. Providing access to ethnically and culturally appropriate health care services is essential to the success of the MassHealth program because of the racial and ethnic diversity of its membership. The MassHealth member population is comprised of:

- Approximately a third of MassHealth's one million members are from racial and ethnic minority populations, with Hispanics constituting the largest ethnic minority group, followed by Portuguese, the fastest growing minority population in Massachusetts.
- About 15% of MassHealth members self-identify speaking a primary language other than English. This may be underreported because all MassHealth applicants, as part of the application process, are asked to voluntarily provide primary language information.
- Massachusetts continues to rank seventh in the nation in the number of recently settled Limited English Proficiency (LEP) populations.
- Approximately 40% of MassHealth members are women aged 18 and older. MassHealth pays for 21% of the births in Massachusetts.
- The Division pays for approximately 17,000, or 21% of births annually in Massachusetts.

The demographic make-up of the state's population has been rapidly changing over the past few years, with a significant influx of refugee and immigrant groups settling into distinct geographic pockets around the state. Through the Division's managed care program MassHealth members are provided access to health care providers in their local communities. The Division's contracted managed care organizations (MCOs) - Boston Medical Center HealthNet Plan, Fallon Community Health Plan, Neighborhood Health Plan, and Network Health - and the Division's own Primary

Care Clinician Plan offer provider networks that include local community health centers and most physicians and physician groups throughout the state.
The Division is committed to continuing its efforts to make the health care marketplace accessible to its diverse membership and to provide the language assistance tools necessary to promote effective oral and written communication during any health care encounter. Some background information on disparities in the provision of health care, MassHealth initiatives to improve the system for ethnic and minority populations, lessons learned and recommendations for the future follow.

Background on Disparities in the Provision of Health Care

During the last two decades significant attention has been placed on the issue of health disparities among racial and ethnic minority groups as evidenced in numerous reports[1] produced by the federal government and private and public institutions. In the Commonwealth of Massachusetts the issue of health disparities has also been continually highlighted through policy reports emanating from the local Department of Public Health, Boston Public Health Commission, Mayor's Task Force on Health, local media and more recently through legislative action to enact the Massachusetts Emergency Room Interpreter Law, July 1, 2001.

While health promotion and disease prevention efforts have improved the overall health of the majority of Americans, significant disparities continue to persist among racial and ethnic minority populations. Massachusetts, like other states, show racial and ethnic minority groups to have disproportionately higher rates for chronic health conditions such as diabetes, hypertension, heart disease, as well as higher preventable hospitalization rates, compared to whites.

Data on maternal and child health indicate the vast majority of Latinas in Massachusetts receive their prenatal care through publicly funded programs. These women are less likely to access the necessary prenatal care resulting in low birth weights and infant mortality for their children.

A variety of factors are said to contribute to disparate health outcomes including: language barriers; lack of printed translated materials; lack of insurance; differences in cultural health beliefs/practices and treatment of illness between practitioner and patients; provider cultural awareness and sensitivity to adequately diagnose and treat diverse patients; and, organizational systems that do not have the tools and resources needed to support the delivery of medical care that is responsive to the needs of racial and ethnic minority groups. These issues all pose unique challenges to MassHealth as a purchaser of health care services for a culturally and ethnically diverse population.

Division Efforts to Address Disparity in the Provision of Health Care

The Division's strategy to continuously improve access to the provision of quality health care for racial and ethnic populations served by MassHealth has been multifaceted and aimed at targeting resources precisely to address some of the barriers to health care cited in existing federal and national reports. Approaches include:

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[1] National and federal reports on difference in health status, health outcomes, and service delivery have been addressed by the Department of Health and Human Services, Centers for Disease Control, National Institutes of Health, Kaiser Family Foundation, Commonwealth Fund, Institute of Medicine, Robert Wood Johnson Foundation, to name a few. Targeted reports have included: *Health People 2010* Report and *National Standards for* Culturally and Linguistically Appropriate Services(CLAS) in Health Care, Institute of Medicine's March 2002 report on *Unequal Treatment* further underscored the issue and made specific recommendations.

Provider-Focused Efforts

- Improving the health care delivery system's capability (i.e.: MassHealth contracted provider network of hospitals, community health centers, mental health centers, independent and group practices, managed care plans, etc.) to enhance patient access to the system, the coordination of medical care and reporting health outcomes data.
- Improving the doctor-patient relationship by providing tools and resources tailored to specific ethnic and racial groups to enhance the clinical care process. These tools include increasing the number of trained medical interpreters or bilingual staff available at MassHealth provider sites to serve the commonly encountered languages spoken by the MassHealth populations served. Reports indicate that the delivery system network will require specific workforce competencies, tools and resources to adequately track and report on health disparities.
- Conducting a Perinatal Care Quality Improvement Project and convening Maternal and Child Health Advisory Group to support MassHealth providers in delivering health care to the Medicaid population.

Member-Focused Efforts

- Targeting MassHealth outreach efforts to enroll people residing in geographic areas where large pockets of non-English speaking populations reside.
- Awarding Health Access Mini-Grants to community based organizations that service low-income racial and ethnic minorities in Massachusetts to promote enrollment and post-enrollment outreach education strategies to improve access to the health care system for MassHealth members.
- Expanding the availability of translated materials available to our members in the ten languages most commonly identified by our members as their primary language. These languages include Arabic, Cambodian, Chinese, French, Haitian, Creole, Laotian, Portuguese, Russian, Spanish and Vietnamese.
- Developing a section on the MassHealth web site dedicated to the health care needs of racial, ethnic populations and populations with a primary language other than English.
- Conducting a Perinatal Care Quality Improvement Project and Maternal and Child Health Advisory Group that identified outreach efforts to ensure that women receive the perinatal care needed to have healthy children
- Collaborating with School-Based Health Centers to provide outreach to female teenagers to promote access to routine health care. This will help to ensure that they will have healthy babies in the future.

Assessment of Healthcare Market Activity (1997-1999)

Over the past number of years the Division gathered information and data to identify specific issues affecting the Massachusetts health care market's ability to address health disparities among minority populations. The Division gathered and compiled information through collaboration with health care industry providers including hospitals and community health centers, academic institutions such as the University of Massachusetts, physician organizations including the Massachusetts Medical Society, African American, Hispanic, Portuguese and Asian constituent groups from different communities and consumer groups including Health Care For All,

Massachusetts Immigrant and Refugee Advocacy Coalition and Area Health Education Centers. Division initiatives to gather information include:

- A provider survey to obtain a profile of MassHealth healthcare delivery sites' ability and capacity to serve members with diverse ethnic and racial background and members whose primary language is not English.
- Examination of the interpreter workforce to identify the supply of and demand for linguistic services.
- A cost benefit study to examine direct and avoided costs of interpreter services in primary care settings.
- A commissioned analysis from the University of Massachusetts Boston Campus Ethnic Minority Policy Institute on the language demographics and educational attainment of ethnic minority groups in Massachusetts.
- A commissioned analysis from the University of Massachusetts Boston Campus Ethnic Minority Policy Institute on the health status of ethnic minority groups and clinical best practice profiles of Massachusetts's minority populations.

Based upon information gathered and conclusions made, the Division identified opportunities for improving the health care system infrastructure and doctor-patient relationship.

Healthcare System Interventions (1996-present) and Lessons Learned

The Division has undertaken numerous interventions to tailor/improve the coordination of clinical care for MassHealth members from racially and culturally diverse populations. Interventions to address the disparity in the provision of health care include:

- Providing medical interpreter training programs for MassHealth health care delivery sites including acute care hospitals and ambulatory providers, to support implementation of Title VI interpreter requirements and the Massachusetts Emergency Room Interpreter Law. Nearing the completion of MassHealth's third fiscal year of offering these statewide trainings, over 500 MassHealth providers will have successfully completed the beginner or advanced course offerings.
- Incorporating uniform standards for cultural and linguistic appropriate services (CLAS) into managed care and fee-for-service provider contracts.
- Supporting a Center for Medicare and Medicare Services funded study to examine racial and ethnic health disparities using HEDIS Medicaid data.
- Providing a cross-cultural training program for medical students and residents delivering health care at institutions serving a high volume of multicultural MassHealth members.
- Testing and improving data collection on MassHealth members' primary languages to identify the predominant language of different geographic regions around the state.
- Improving coordination of patient clinical care for racial and ethnic minority populations (1999-present)
    - Developed cross-cultural guidelines to improve diagnosis and clinical decision-making in diabetes care management.
    - Developed patient clinical education that promotes awareness and participation in chronic disease self-management

  - Require acute hospital providers to develop quality improvement projects aimed at disparate health outcomes among racial, ethnic and linguistic populations.
- Most recently, the Division was awarded a contract with the Department of Health and Human Service Agency's Office of Minority Health to develop and test cross-cultural clinical guidelines for primary care clinicians serving culturally diverse MassHealth populations.

The lessons learned from undertaking these efforts suggest that considerable work remains to be done prior to addressing accountability for reducing disparities in health status and outcomes. Evaluating and monitoring disparate health outcomes will require investing significant resources and time to improve the infrastructure of the health care delivery system. This includes such areas as information systems technology, building workforce knowledge and provider skills, and maintaining partnerships with healthcare industry stakeholders.

Division Recommendations

The information gathered from our efforts and ongoing coordination of and sharing efforts with Massachusetts health care industry providers to address disparities in the provision of health care indicate challenges remain that need to be met prior to analyzing disparities in health outcomes.

The Division has the following recommendations to meet these challenges:

1) *Work with the legislature and all state agencies to share information and develop uniform approaches, when possible, to address racial and ethnic differences when providing services to culturally diverse populations in the state.*

2) *Develop incentives for providers to put critical system level solutions in place, such as training staff, providing interpreter services and improving information systems to monitor access and utilization of health care by language spoken, to improve tracking and monitoring of health care utilization and health outcomes.*

3) *Identify specific measures that aid in tracking and monitoring the health status of racial and ethnic minority subgroups with the worst health outcomes in Massachusetts.* The Division has started this by requiring acute hospitals to implement quality initiatives to report clinical outcomes by race, ethnicity and Spanish language. The Division also requires hospitals to report emergency room, maternity and asthma care utilization by race, ethnicity and Spanish language.

4) *Develop and maintain partnerships with medical schools, health industry stakeholders, and state agencies to establish standards for cross-cultural training programs to improve workforce competency skills.* The Division has been working with the University of Massachusetts Medical School on clinical best practices that incorporate cultural issues to improve health outcomes in Medicaid populations. The Division has also worked with Harvard Medical School to develop and provide training for their staff and students on cultural issues in the provision of health care.

5) *Develop partnerships with physicians and primary care providers to establish cross-cultural clinical care guidelines that reduce bias in clinical decision-making based on race, ethnicity, and language.*

Thank you for the opportunity to provide the Committee with an overview of MassHealth's response and recommendations for health policies for serving ethnically and racially diverse populations. We look forward to collaborating with the legislature, state agencies and the health care community to identify and implement initiatives to continue to improve the provision of health care to ethnic and minority populations throughout the Commonwealth.

For more information contact Sarah Barth at (617) 210-5405.

The Commonwealth of Massachusetts
Executive Office of Health and Human Services
Division of Medical Assistance
600 Washington Street
Boston, Massachusetts 02111

JANE SWIFT
Governor

ROBERT P. GITTENS
Secretary

WENDY E. WARRING
Commissioner

June 11, 2002

Chairman Richard T. Moore
Joint Committee on Health Care
Room 312-D
State House
Boston, MA 02133

Dear Chairman Moore:

I am writing in follow-up to the June 4 Joint Committee on Health Care oversight hearing on racial and ethnic disparities in the provision of health care in Massachusetts. As I testified to on Tuesday, since 1996 the Division has focused considerable effort to continually improve the cultural competency of the provision of health care to MassHealth members. We look forward to sharing information we have gathered and lessons learned with other groups in the Commonwealth, including the Massachusetts Medical Society (MMS), to aid in ensuring that health care is provided to all citizens in Massachusetts with sensitivity to diverse cultural, racial and ethnic backgrounds and primary language spoken.

I would like to provide additional information in answer to questions posed to me by the Committee last Tuesday.

1. Success of cross-cultural medical training programs and extending the trainings to practicing physicians – You are correct in that cross-cultural trainings have only been provided to medical students. The cross-cultural medical training programs were conducted by the University of Massachusetts Medical School's Massachusetts Access Project (MAP). Trainings were first provided through a MassHealth partnership with MAP and have since been continued by the medical school. The core goals of the training were achieved, resulting in development of increased linguistic and cultural competence of medical students participating in the Division-funded project. MAP asserts that most student and resident participants are joining medical practices that serve large MassHealth patient populations in the Commonwealth. A copy of MAP's fiscal year 2000 report is enclosed.

   The Division is interested in working with the MMS to provide similar trainings to medical providers serving MassHealth members. We will also share information and lessons learned with MMS so that it may extend similar trainings

to the rest of the health care industry in the Commonwealth. The Division and MMS are currently coordinating a date for an initial meeting to discuss collaborating efforts on cultural competency initiatives.

2. Copy of MassHealth provider survey – Enclosed is a copy of the provider survey designed to obtain a profile of MassHealth healthcare delivery sites' ability and capacity to serve members with diverse ethnic and racial backgrounds and members whose primary language is not English. The Division is unlikely to repeat the survey at this time since administration of the survey was costly. Results of the survey provide a broad overview of the cultural and ethnic distribution of the MassHealth population and the types of activities and efforts undertaken by providers to address the cultural and linguistic differences within the MassHealth population. The report identifies the distribution of the Hispanic/Latino population across MassHealth sites, frequency of the top two minority groups served listed at sites, and distribution of the Non-English languages spoken by MassHealth members by sites. Key findings include:

    - Great diversity exists across MassHealth service delivery sites on a number of dimensions including: race; ethnicity; nationality; language; and religion.
    - More than 1/3 of MassHealth sites with 30+% MassHealth participation have observed racial, ethnic, or cultural variation in: appointment making and keeping; communication during the health interview; and compliance with treatment regimens. A majority of sites noticing racial, ethnic, and cultural variation in these areas of the health care visit report that they have strategies in place for addressing these areas to improve health care delivery.
    - Suggested topics for future training identified by MassHealth site staff fall under the following headings: Staff Communication Skills, Patient Education; Community Resources; Preventive Health Care; Disease Specific Training; and Administrative Issues.

3. Adapting the MassHealth Provider Survey to the Uncompensated Care Pool - The Committee inquired whether the survey might be adapted to the uncompensated care pool. It might be worth looking at the results of the survey and targeting those providers who serve a high volume of uncompensated care pool users to determine whether they are experiencing similar issues. Section VII of the report, discussing the continuing training needs of MassHealth providers, may also prove helpful for providers serving the uncompensated care pool population. It is important to note, however, that the Center for Survey Research conducted the survey exclusively to examine issues affecting the MassHealth population. I have enclosed the survey findings to aid in determining its adaptability to the pool population.

> The Committee may want to also review more recent provider surveys. The Office of Minority Health at the federal Department of Health and Human Services may be of particular help identifying more recent surveys.

I hope that the enclosed materials prove helpful to the Committee. If you have further questions, please contact me at (617) 210-5690, or Sarah Barth of my staff at (617) 210-5405.

Sincerely,

Wendy E. Warring
Commissioner

UMASS
MEDICAL
SCHOOL

MassHealth Access Program
Office of Community Programs
University of Massachusetts Medical School

MassHealth Pathway on Multicultural Medical Training for Students and Residents:

A Pre-Clinical International Track
and
A Clinical Scholars Program on Underserved and Multicultural Populations
Year End Report
FY 2000

Submitted by:
Dr. Michael Godkin and
Monica Escobar Lowell for the
MassHealth Access Program

The MassHealth Access Program is a collaborative between the University of Massachusetts Medical School and the Division of Medical Assistance

Executive Summary AY2000
MassHealth Pathway on Multicultural Medicine

Project Purpose:

This project has two (2) main goals:

1) To develop linguistic cultural and clinical skills of medical students and Family Practice residents to better enable them to serve MassHealth patients who are immigrants and refugees.
2) To develop peer teachers who train other students and residents in multiculturalism.

During the preclinical years, the training of students has three (3) components: an assignment to a family in Massachusetts of a language group whose language the student wishes to study so that the student can learn about the family's culture, health beliefs and practices, and barriers to health and social services; a six week language and cultural immersion abroad at the end of the first year of medical school; and a community service project in Massachusetts during the second year of medical school in which students serve the same language group whose language they learned in the summer. These students then serve as peer teachers about multiculturalism.

The training of clinical students and residents is achieved largely by having them participate in language and clinical electives in countries where they can develop skills that will enable them to serve MassHealth patients. Upon return, participants serve as peer teachers to other students and residents with respect to multiculturalism.

Accomplishments/Milestones:

The core goals have been achieved. As shown below the linguistic and cultural competence of students in the DMA funded project has been developed. In addition, a large majority of student and resident participants are graduating into practices in Massachusetts that serve large Medicaid patient populations. Student and resident participants have become peer leaders in multiculturalism training. Specific outcomes include:

1) Fifteen preclinical students, fourteen clinical students and six Family Practice residents participated in the program in AY2000.

2) Trainees received language, cultural and clinical training in the following countries: Vietnam, Taiwan, Nepal, India, Zimbabwe, Cuba, Venezuela, Honduras, Guatemala, Bolivia, Ecuador, Mexico and Costa Rica.

3) Of the fourteen clinical years trainees (see attached summary chart), three are still in school. Of the remaining eleven, nine have entered primary care residencies, one is in an obstetrical residency and one has gone into dermatology. Seven of these eleven are in residencies in Massachusetts; the rest stayed in New England. All students submitted written reports based on the attached guidelines.

4) Of the twelve residency trainees who did international electives in the past two years, four are still in training and seven have become providers in Massachusetts (see attached summary).

5) Fourteen preclinical students participated in a summer language and cultural immersion in Latin America; one student studied Mandarin in Taiwan (see attached summary of their names and destinations).

6) Two residency trainees have developed a curriculum on multiculturalism that is being introduced into the Family Practice Residency Program (see attached).

7) A journal article assessing the impact of the program on cultural competence has been accepted in Family Medicine (see attached). Briefly, with respect to evaluation, students in the preclinical component of the program are a distinct group when entering the program. They differ from their classmates with respect to significant differences in 9/20 attitudes consistent with serving the underserved and 12/43 items, which represent significantly higher levels of cultural competency. In addition, on five other items, the trend was in the direction of participating students having higher levels of cultural competency ($p<.1$).

   In no instance did non-participants have significantly ($p<.05$) higher scores on attitudes consistent with serving the underserved. In two items on the cultural competency continuum, the participating students thought they were less aware of how their own cultural background had affected their attitudes and beliefs about other cultures and they thought they were less able to incorporate cultural issues into a treatment plan. In addition, participating students more often felt unsafe in communities of color at a level approximating significance ($p=.06$).

With respect to the impact of the program, post-tests indicated that participants have significantly higher levels of cultural competence than non-participants on 14/43 measures, and in an additional three items, participating students had higher levels approximating significance ($p<.1$). In no instance did non-participants score significantly higher.

An analysis of pre and post surveys for only the cohort in the program indicated that participants had a significant increase in 11/12 measures of knowledge about other cultures, including their cultural beliefs, health beliefs and practices and health needs. The self-assessment instrument measuring cultural competence is attached.

8) In AY 2000, preclinical students in their second year of the Pathway completed year-long community service projects in Massachusetts. Projects included the following: free clinics, soup kitchen, flu shot program, mentoring program, nursing home and Worcester Boys and Girls Club.

9) An analysis of the linguistic competence of fourth year medical students showed that DMA-funded students, who had participated in language training abroad at the end of their first year, used Spanish significantly more often than their peers in seven areas of the doctor-patient relationship (greetings, introductions, partial history, complete history, counseling, treatment instructions, and serving as interpreter).

10) Preclinical years students in Class of 2003 successfully completed a family assignment with an immigrant or refugee family in Massachusetts. Reports of these experiences were based on the attached protocol.

11) Family Practice residency trainees gave talks about their experiences to other residents and faculty at their health centers.

12) Preclinical student trainees served as peer teachers on multiculturalism in the Physician, Patient and Society Course.

13) Two clinical years students gave presentations on multiculturalism to the whole class below them.

Clinical Years Participants (AY 2000)

Name	Country	Residency Status	State
Benoit, Stephen	Honduras	Preliminary Medicine	Rhode Island
Condit, Bruce	Bolivia	Family Medicine	Massachusetts
Silk, Laura	Costa Rica	OB	Connecticut
McCormack, Mollie	Cuba	Dermatology	Massachusetts
Gerweck, Ken	Mexico	Family Practice	Massachusetts
Gates, Christine	Mexico	Family Practice	Maine
Buchanan, Stephen	Venezuela	Family Practice	Massachusetts
Remis, David	Mexico	Medicine-Pediatrics	Massachusetts
O'Donnell, Caitlin	Costa Rica	Family Practice	Massachusetts
Bolduc, Phil	Costa Rica	Family Practice	Massachusetts
Chin, Michael	Zimbabwe	Family Practice	Rhode Island
Coughlin, Dennis	Nepal	UMMS, Class of 2001	
Armani, Anne Marie	France	UMMS, Class of 2001	
Conway, Karen	India	UMMS, Class of 2001	

Preclinical Years Participants (AY 2000)

Name	Country
Perry, Ylfa	Ecuador
Murphy, Sarah	Guatemala
Lozano, Sarah	Mexico
Gaffin, Jonathan	Costa Rica
Sedgwick, Peter	Ecuador
McPhee, James	Ecuador
Palumbo, Andrea	Costa Rica
Archibald, Sarah	Guatemala
McNulty, Brendan	Costa Rica
Fray, Elizabeth	Costa Rica
Chou, Cinnie	Taiwan
Davis, Catherine	Costa Rica
Davis, Margaret	Guatemala
Conners, William	Venezuela
Bayon, Laura	Ecuador

Cross Cultural Curriculum GNOME
Heidi Ginter, MD
12/2/1999

GOAL

All graduates of the UMASS Family and Community Medicine Residency will incorporate aspects of culture into every patient encounter with improved quality in all aspects of patient care.

NEEDS ASSESSMENT

1) Faculty representatives (one from each health center)
2) All residents
3) Questions will come from the book that Mick has. Similar to the surveys we did for the international electives.

OBJECTIVES (K=knowledge, S=skills, A=attitudes)

By the end of this curriculum, residents will know:

1) How to take a cultural history (Kleinman's questions) (S)
2) How to use an interpreter properly (S)
3) The difference between immigrant and refugee and their needs (K)
4) Basic information on predominant minority cultures served by their health center in Worcester (reflecting the common experience of OB and S6) (K)
5) Disease-specific risk factors and appropriate treatments (K)
6) Some major health beliefs and how to acquire more information (K)
7) Issues around access and its ramifications for health (K)
8) How the provider's cultural beliefs impact care (A)
9) The importance of culture in every patient encounter (A)
10) How to use cultural information effectively and avoid stereotyping (A)

METHODS *(numbers correspond to Objectives)*

1) Small group setting where Kleinman's questions are distributed along with specific case examples that are discussed. Also could role play the cases. Also could view video of providers taking cultural histories: highlighting good examples and ones that might need improvement. Could use second year conferences. Develop CD-Rom interactive learning module.
2) Have orientation time for each new group on S6 that discusses this and demonstrates it.
3) Definitions and examples could be part of a packet. Reference to this packet could be made by attendings when it is relevant to patient c are either inpatient or in health centers. Could be addressed in chart rounds when there is an appropriate case.
4) Could be part of a packet of articles providing basic historical and demographic information for each health center that is distributed during community medicine month.
5) Could be part of a packet of articles. Information is highlighted by attendings in inpatient and outpatient settings whenever relevant.
6) Could be part of a packet of articles. Could also be addressed by community speakers or residents at noon conferences at the health centers or Grand Rounds. Could use second year weekly conferences.
7) Grand Rounds.
8) Small group exercises and discussion.
9) Chart reviews should look for evidence that culture was addressed and suggest ways to improve care with this in mind. Feedback on this issue when clinical care is being directly observed or reviewed on video.
10) Small group discussions. Have case examples, either written or on video, to discuss. Develop CD-ROM interactive learning module.

EVALUATION *(numbers 1-10 correspond to Objectives and Methods)*

1) Competence assessed by group facilitator. Should also be assessed in actual clinical setting by direct observation or review of video-taped patient care.
2) Ask interpreters in the hospital and health centers to complete brief evaluation forms of residents. Can also ask for patients' perceptions directly or via the interpreter's impressions.
3) Assess care of these patients via chart audits and in semi-annual performance reviews.
4) Faculty can make overall assessment during precepting in health center and when working on hospitalized patients with residents. Can be incorporated into semi-annual performance reviews, S6 evaluation, and community medicine month evaluation.
5) Faculty can make overall assessment during precepting in health center and when working on hospitalized patients with residents. Can be incorporated into semi-annual performance reviews and S6 evaluation. Should get input from BVV and community attendings.
6) If resident does a presentation this can be evaluated.
7) At health centers attendings can observe how residents address the issue of access for their patients and provide feedback in semi-annual review and PRN throughout the year when observed.
8) Evaluation by the group facilitator.
9) Chart reviews and feedback on directly observed clinical care and video-taped clinical care.
10) Evaluation by group facilitator. Some evaluation component through CD-ROM?
11) Change current evaluation forms to include an item for recognizing cultural issues in patient care.

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Participation in Research and Access to Experimental Treatments by HIV-Infected Patients

[Special Article]

Gifford, Allen L.; Cunningham, William E.; Heslin, Kevin C.; Andersen, Ron M.; Nakazono, Terry; Lieu, Dale K.; Shapiro, Martin F.; Bozzette, Samuel A.

For the HIV Cost and Services Utilization Study Consortium
From the Center for Research in Patient-Oriented Care and the Quality Enhancement Research Initiative in HIV, Veterans Affairs San Diego Healthcare System, San Diego (A.L.G., D.K.L., S.A.B.); the University of California, San Diego, School of Medicine, La Jolla (A.L.G., D.K.L., S.A.B.); the University of California at Los Angeles, Los Angeles (W.E.C., K.C.H., R.M.A., T.N., M.F.S.); and RAND Health, Santa Monica (M.F.S., S.A.B.) - all in California.
Address reprint requests to Dr. Gifford at the Veterans Affairs San Diego Healthcare System and the University of California, San Diego, 3350 La Jolla Village Dr. (111N-1), San Diego, CA 92161, or at agifford@ucsd.edu.

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Abstract

Background: Although there is concern that minority groups and women are underrepresented in research involving patients with human immunodeficiency virus (HIV) infection, the available data are inconclusive.

Methods: We used nationally representative data from the HIV Cost and Services Utilization Study to determine the characteristics of the participants and nonparticipants in trials of medications for HIV infection and whether or not patients had access to experimental treatments. A probability sample of 2864 persons, representing all 231,400 adults with known HIV infection who are cared for in the contiguous United States, were interviewed on three occasions between 1996 and 1998. They were asked about participation in clinical research studies of medications and past receipt of experimental medications for HIV.

Results: We estimate that 14 percent of adults receiving care for HIV infection participated in a medication trial or study; 24 percent had received experimental medications; and 8 percent had tried and failed to obtain experimental treatments. According to multivariate models, non-Hispanic blacks and Hispanics were less likely to be participating in trials than non-Hispanic whites (odds ratio for participation among non-Hispanic blacks, 0.50 [95 percent confidence interval, 0.28 to 0.91]; odds ratio among Hispanics, 0.58 [95 percent confidence interval, 0.37 to 0.93]) and to have received experimental medications (odds ratios, 0.41 [95 percent confidence interval, 0.32 to 0.54] and 0.56 [95 percent confidence interval, 0.41 to 0.78], respectively). Patients who were cared for in private health maintenance organizations were less likely to participate in trials than those with fee-for-service insurance (odds ratio, 0.43 [95 percent confidence interval, 0.21 to 0.88]). Women were not underrepresented in research trials and had a similar likelihood of receiving experimental treatments.

Conclusions: Among patients with HIV infection, participation in research trials and access to experimental treatment is influenced by race or ethnic group and type of health insurance. (N Engl J Med 2002;346:1373-82.)

Clinical research should involve diverse populations of patients. [1-3] Race, sex, and other sociodemographic factors can influence the course of disease, the response to treatment, the types of toxic effects, and health-related behavior, and the degree of diversity can therefore affect the generalizability of the results. [4-9] Choosing research cohorts that resemble the target clinical population may improve the likelihood that new therapies will be accepted by patients and their doctors. Many patients with serious diseases have few or no options for conventional treatment, so enrollment in trials of experimental treatments or new applications of existing medications can be the only means of access to needed care. [10,11]

Human immunodeficiency virus (HIV) infection is a case in point. The course of HIV disease is affected by the biology of the host and socially influenced health-related behavior. Those with HIV often have special needs and few options: their median household income is about one third that of typical households in the United States; they are four times as likely to be members of an underserved minority than to be white; and conventional therapy for HIV commonly fails. [12-14]

Available studies suggest that minority groups and women are underrepresented in trials of treatment for HIV infection. However, these studies lack accuracy and detail because they have been confined to selected sites or because they compare the proportions of known trial participants of different races or ethnic groups and sexes with estimates of the proportions in the overall population. [15-18] Although such comparisons are attractively simple, they are problematic, because data from most privately funded trials, unpublished studies, and expanded-access programs are unavailable; because the local or national surveillance data used for comparison may not represent all the patients for whom investigational therapies would be appropriate; and because the characteristics of persons who do not participate in trials are not accounted for. [19-21] To address these issues, we used nationally representative data from the HIV Cost and Services Utilization Study (HCSUS) to determine the characteristics of the participants in trials of medications for HIV and whether or not patients with HIV had access to research trials and experimental treatments.

Methods

Sources and Weighting of Data

We analyzed data from the HCSUS sample, which represents all adults 18 years of age or older who were receiving care for known HIV infection in the 48 contiguous United States in early 1996, except those who were cared for only in prison or active-duty military facilities or emergency departments. [22,23] We used multistage sampling methods to assemble the study population of 2864 persons; we used related methods to construct analytic weights with which we adjusted the survey data to represent the entire reference population of 231,400 adults receiving care for HIV in the contiguous United States outside of the military, prisons, and emergency rooms. We constructed weights using each patient's probabilities of being sampled and of visiting the care site during the study period. Characteristics of those who did not respond to the full survey were collected and used to increase weights for the respondents most similar to nonrespondents. [23] Details of the sampling and survey methods and interview questions are available elsewhere. [22-26]

Interviews

The RAND institutional review board and, when available, a local board, reviewed and approved all forms, materials, and procedures. After written informed consent had been given, participants were interviewed, usually in person, on three occasions (once between January 1996 and April 1997, once between December 1996 and July 1997, and once between August 1997 and January 1998). Interviews were conducted in English or Spanish, by centrally trained research personnel using computerized personal interviewing devices and locally identified and approved interpreters for interviews in languages other than English or Spanish. All interviewers had full access to survey experts and investigators for any questions that arose in the field.

Classification of Respondents

During the base-line interview, we collected information on sociodemographic characteristics, risk factors for exposure to HIV, health insurance, and attitudes and beliefs. Race or ethnic group was determined on the basis of the answer to the question "Which of these would you say is your main racial or ethnic group?" The response options included non-Hispanic white, non-Hispanic black, Hispanic, American Indian or Alaskan Native, Asian or Pacific Islander, mixed race, or some other single race. Subgroups defined according to risk factors for HIV were mutually exclusive. Participants with intravenous drug use were so classified. Men who did not use intravenous drugs but who had sex with other men were classified as men who have sex with men. Those who fell into neither of these categories and who were heterosexually active were so classified, unless they had been infected with HIV through blood products. Persons infected through blood products and those without defined risk factors for exposure to HIV were classified as "other." [27]

Participation in Research and Access to Experimental Medications

The response options were chosen to minimize the possibility of errors of omission or misclassification regarding whether those interviewed were participants in trials. We assessed participation in medication trials by the answers to the questions "Are you currently participating in any clinical trials or clinical research studies?" and "What services are being provided in the trial [or trials]?" Respondents chose among specific options regarding the provision of medications, medical care, and checkups, alone or in combination.

Patients obtained experimental medications through clinical trials or approved clinical protocols involving investigational new drugs. Expanded-access programs, programs based on the compassionate use of investigational new drugs, and parallel-track protocols are Food and Drug Administration-approved mechanisms to allow doctors and patients in the United States to obtain promising experimental HIV drugs. [11] We assessed the lifetime history of use of experimental treatments by the answer to the question "Have you ever tried to get experimental drugs or treatments through a clinical trial or expanded access?" Those who answered "yes" were asked, "Were you able to get experimental drugs or treatments when you tried to?" We calculated the perceived unmet need for experimental medications as the proportion of patients who tried but failed to obtain them. We used data abstracted from medical records to validate clinical measures and receipt of treatments.

Other Variables

Participants were asked two questions about each of the following issues in order to rate them on a Likert scale: their trust in providers, their desire for health information, and their participation in decisions about treatment (Cronbach's alpha for internal consistency, 0.86, 0.64, and 0.76, respectively). They were asked one question about their attitude toward antiretroviral medications. [26,28-31]

We used a Web-based system (http://www.randmcnally.com/) to calculate the distance from each participant's primary care site to the nearest site where research on HIV was being conducted by an AIDS Clinical Trials Group (ACTG) or one of the Community Programs for Clinical Research on AIDS (CPCRA) during the HCSUS field period.

Comparison Data

To provide a context for our findings, we assembled basic sociodemographic data for all participants in ACTG trials who were enrolled between 1996 and 1998 (i.e., during the HCSUS field period) and for participants in studies of HIV drugs published in the English-language literature. [32] Studies were identified by a Medline computer search for 1996 through 2000 with the keywords "HIV infections" and "drug therapy" and with results limited to reports on clinical trials. We reviewed the abstracts of articles to identify primary reports and to eliminate pediatric studies and studies conducted outside the United States. We abstracted and totaled the data on participants from the articles we identified. Details are provided in Supplementary Appendix 1 (available with the full text of this article at http://www.nejm.org). Finally, we obtained data from reports by the Centers for Disease Control and Prevention (CDC) on the race or ethnic group and sex of all patients with AIDS in the United States. [33]

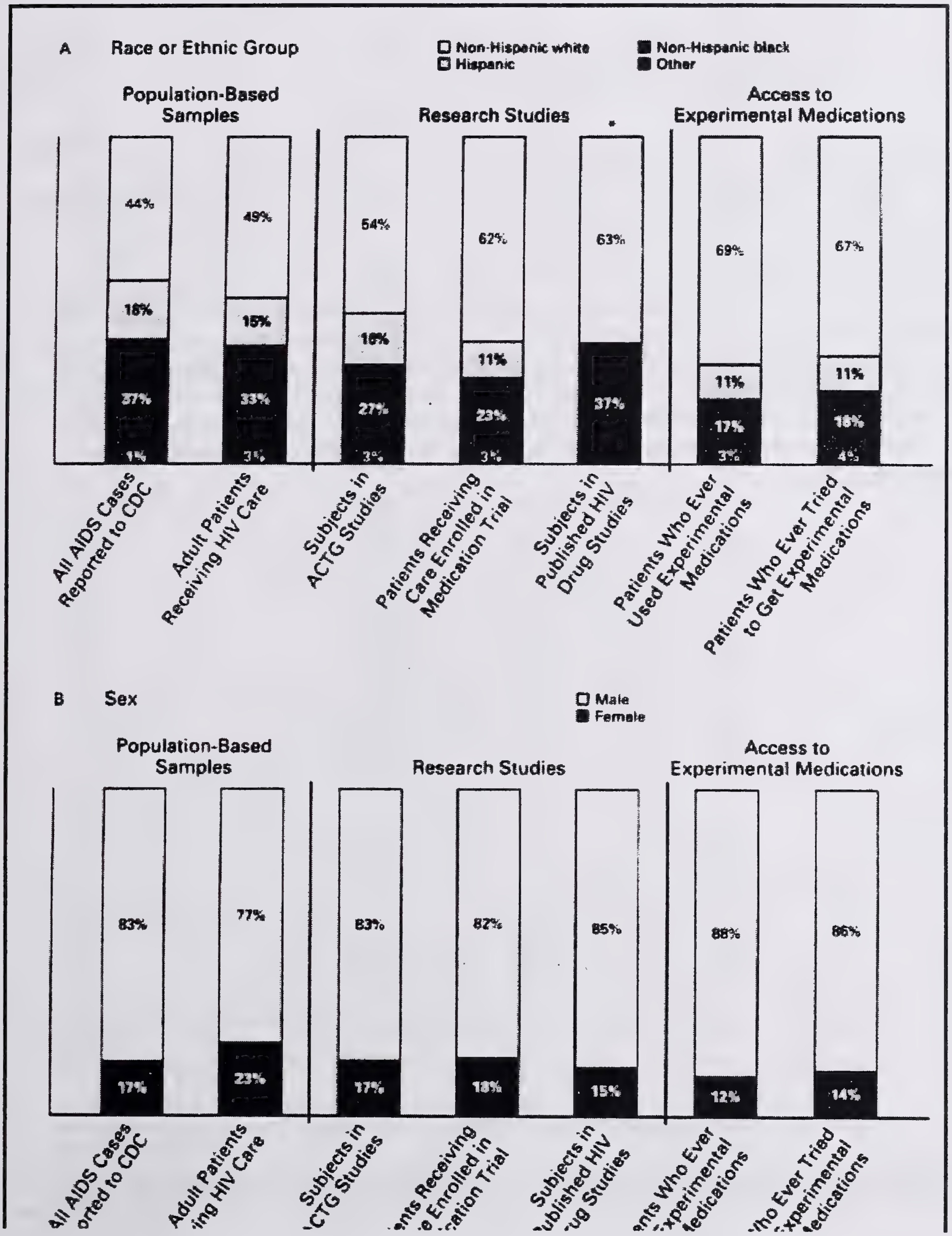
Statistical Analysis

All analyses of HCSUS data were weighted and adjusted for the complex sampling design with the use of the Taylor series linearization method, and all P values are two-tailed. [34] We used "hot deck" imputation to fill in missing values, which accounted for less than 5 percent of data on CD4+ lymphocyte counts, less than 3 percent of data on insurance and income, and less than 0.5 percent of data for other essential variables. [35] We identified univariate predictors of participation in medication trials, of lifetime use of experimental treatments from a study or expanded-access program, and of perceived unmet need for experimental treatments. We estimated multivariate logistic-regression models to determine which factors were independent predictors of participation in research on medication for HIV infection and of lifetime use of experimental medications.

Results

Race or Ethnic Group

On the basis of our data, we estimate that, in 1996, 62 percent of HIV-infected adults participating in medication trials were white, whereas only 49 percent of all those receiving care for HIV infection were white. At that time, whites accounted for 44 percent of the patients with AIDS whose cases had been reported to the CDC (Figure 1). Blacks accounted for 23 percent of the adults participating in treatment trials but for 33 percent of those receiving care for HIV infection and 37 percent of patients with reported AIDS cases. The percentage of trial participants who were white was similar to the 63 percent in published, peer-reviewed HIV studies and higher than the 54 percent of ACTG enrollees. These data suggest that whites are overrepresented in clinical trials related to HIV. [22,32,33] The proportions of women in the various research and clinical groups were similar (Figure 1).



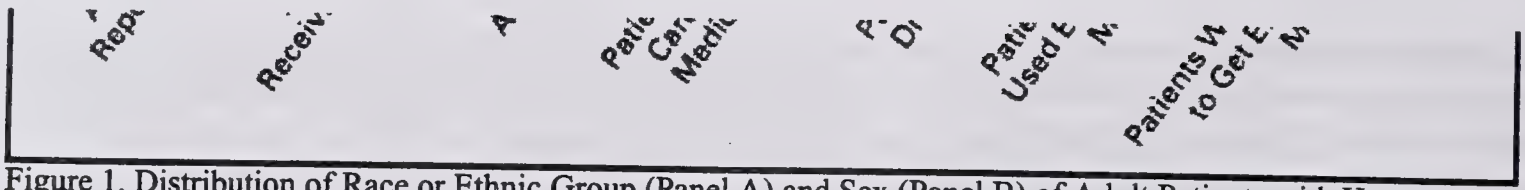
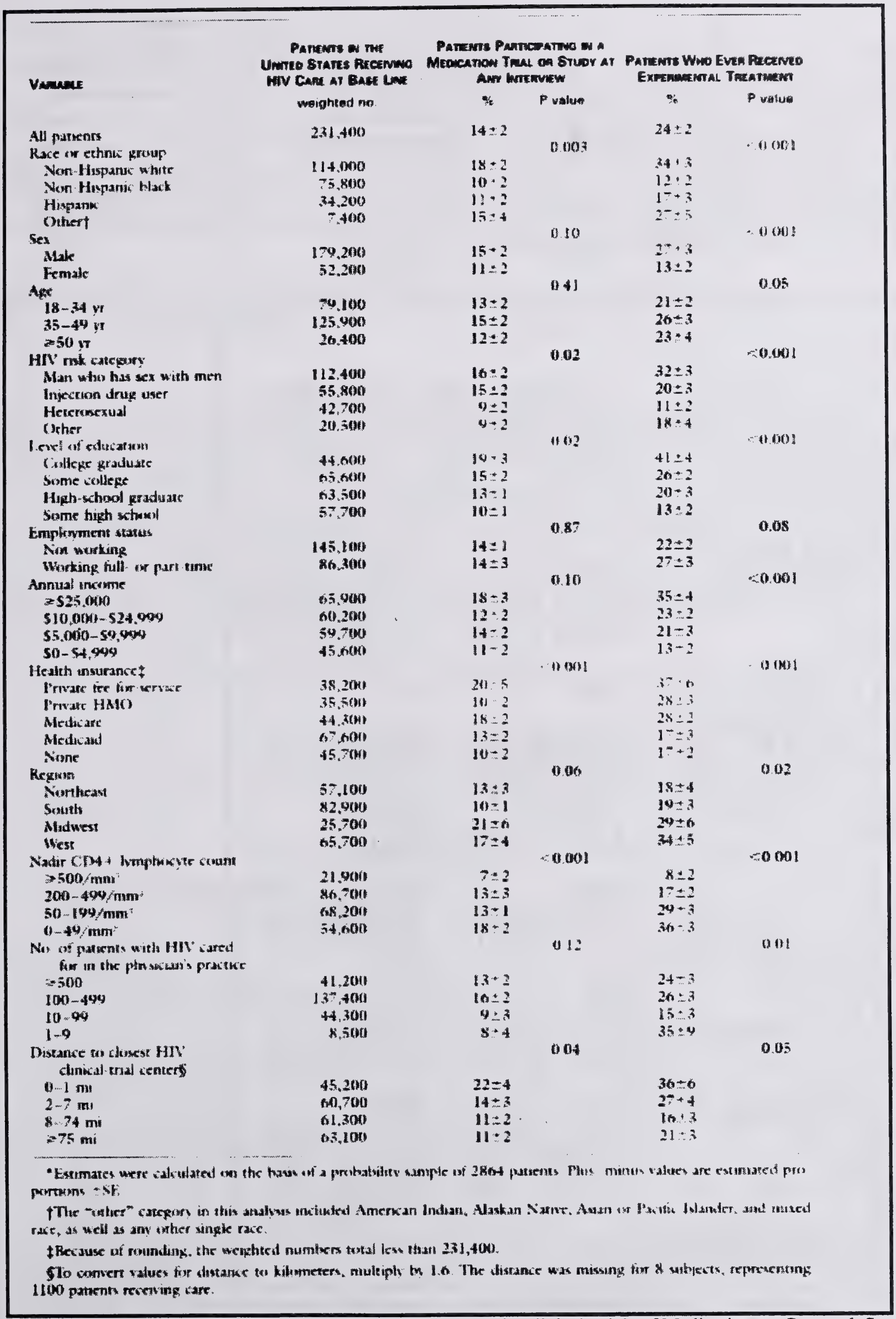


Figure 1. Distribution of Race or Ethnic Group (Panel A) and Sex (Panel B) of Adult Patients with Human Immunodeficiency Virus (HIV) or the Acquired Immunodeficiency Syndrome (AIDS) in Population-Based Samples, Research Studies, and Access to Experimental Medications between 1996 and 1998. Some published studies of HIV drugs (18 percent of the studies, accounting for 17 percent of study subjects) reported race as white or nonwhite only; therefore, for subjects in published HIV drug studies (indicated by the asterisk), only white and nonwhite proportions are shown. CDC denotes Centers for Disease Control and Prevention, and ACTG AIDS Clinical Trials Group. Because of rounding, percentages may not total 100.

Predictors of Participation in Research

Examination of population-based participation rates showed that, during the two years of follow-up in HCSUS, an estimated 14 percent of the 231,400 HIV-infected adults who had been receiving HIV care in early 1996 participated in a medication trial or study; 24 percent received experimental treatment at some time during the course of their HIV treatment; and 8 percent tried and failed to obtain experimental treatments. Race or ethnic group, the primary risk factor for HIV, level of education, type of health insurance, severity of HIV disease, proximity to a major clinical-trial center (ACTG or CPCRA), and attitudes toward health care providers and HIV medications were significantly associated with participation or lack of participation in medication trials according to univariate analyses. The differences among subgroups were substantial: non-Hispanic black race, less than a high-school education, private insurance through a health maintenance organization (HMO), and receipt of primary care 8 miles (12.8 km) or more from a major clinical-trial center were each associated with a reduction of about 50 percent in the likelihood of participating in a medication trial (Table 1).



Variable	Patients in the United States Receiving HIV Care at Base Line	Patients Participating in a Medication Trial or Study at Any Interview		Patients Who Ever Received Experimental Treatment	
	weighted no.	%	P value	%	P value
All patients	231,400	14±2		24±2	
Race or ethnic group			0.003		<0.001
Non-Hispanic white	114,000	18±2		34±3	
Non-Hispanic black	75,800	10±2		12±2	
Hispanic	34,200	11±2		17±3	
Other†	7,400	15±4		27±5	
Sex			0.10		<0.001
Male	179,200	15±2		27±3	
Female	52,200	11±2		13±2	
Age			0.41		0.05
18–34 yr	79,100	13±2		21±2	
35–49 yr	125,900	15±2		26±3	
≥50 yr	26,400	12±2		23±4	
HIV risk category			0.02		<0.001
Man who has sex with men	112,400	16±2		32±3	
Injection drug user	55,800	15±2		20±3	
Heterosexual	42,700	9±2		11±2	
Other	20,500	9±2		18±4	
Level of education			0.02		<0.001
College graduate	44,600	19±3		41±4	
Some college	65,600	15±2		26±2	
High-school graduate	63,500	13±1		20±3	
Some high school	57,700	10±1		13±2	
Employment status			0.87		0.08
Not working	145,100	14±1		22±2	
Working full- or part-time	86,300	14±3		27±3	
Annual income			0.10		<0.001
≥$25,000	65,900	18±3		35±4	
$10,000–$24,999	60,200	12±2		23±2	
$5,000–$9,999	59,700	14±2		21±3	
$0–$4,999	45,600	11±2		13±2	
Health insurance‡			<0.001		<0.001
Private fee-for-service	38,200	20±5		37±6	
Private HMO	35,500	10±2		28±3	
Medicare	44,300	18±2		28±2	
Medicaid	67,600	13±2		17±3	
None	45,700	10±2		17±2	
Region			0.06		0.02
Northeast	57,100	13±3		18±4	
South	82,900	10±1		19±3	
Midwest	25,700	21±6		29±6	
West	65,700	17±4		34±5	
Nadir CD4+ lymphocyte count			<0.001		<0.001
≥500/mm^3	21,900	7±2		8±2	
200–499/mm^3	86,700	13±3		17±2	
50–199/mm^3	68,200	13±1		29±3	
0–49/mm^3	54,600	18±2		36±3	
No. of patients with HIV cared for in the physician's practice			0.12		0.01
≥500	41,200	13±2		24±3	
100–499	137,400	16±2		26±3	
10–99	44,300	9±3		15±3	
1–9	8,500	8±4		35±9	
Distance to closest HIV clinical-trial center§			0.04		0.05
0–1 mi	45,200	22±4		36±6	
2–7 mi	60,700	14±3		27±4	
8–74 mi	61,300	11±2		16±3	
≥75 mi	63,100	11±2		21±3	

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*Estimates were calculated on the basis of a probability sample of 2864 patients. Plus–minus values are estimated proportions ±SE.

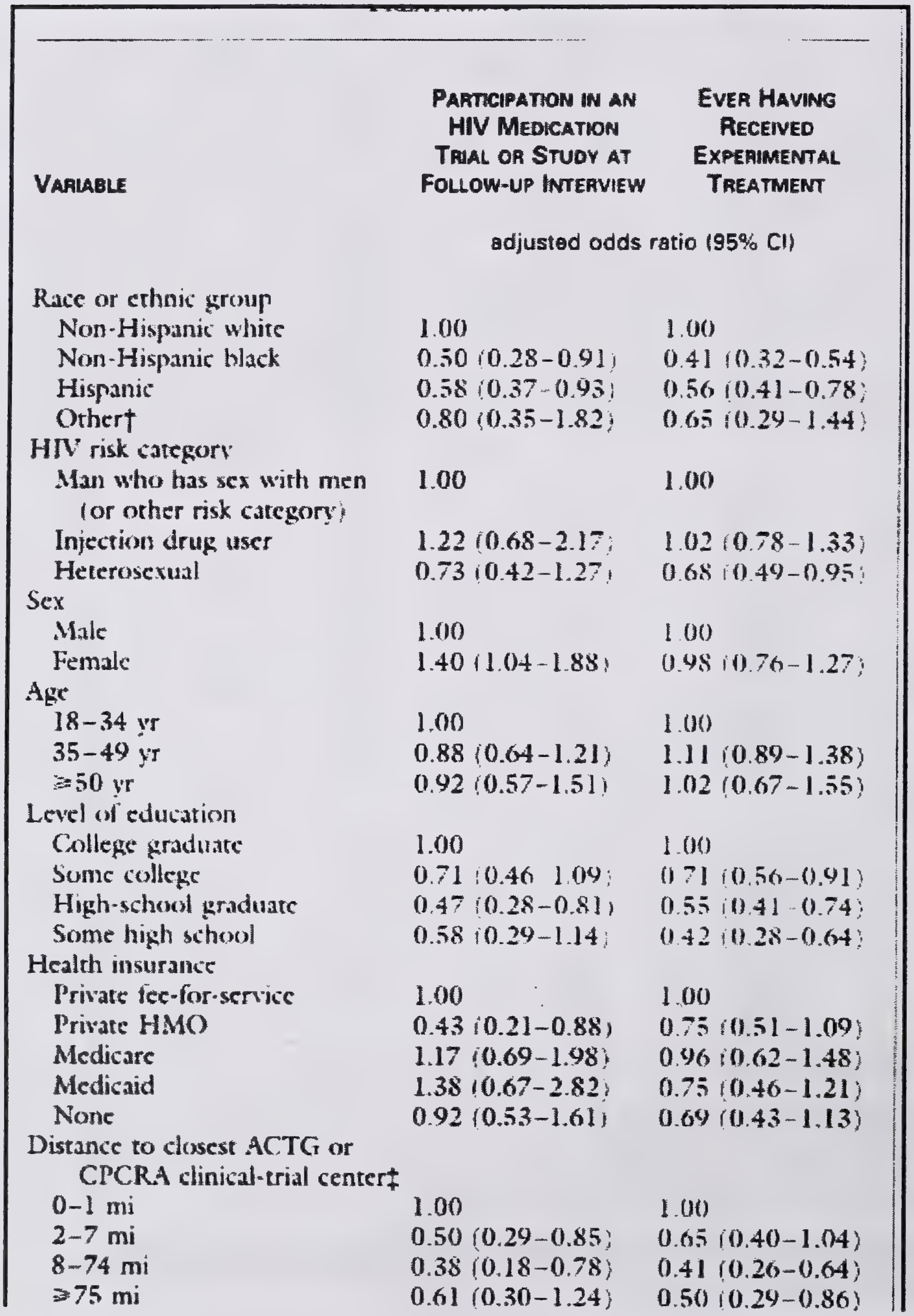
†The "other" category in this analysis included American Indian, Alaskan Native, Asian or Pacific Islander, and mixed race, as well as any other single race.

‡Because of rounding, the weighted numbers total less than 231,400.

§To convert values for distance to kilometers, multiply by 1.6. The distance was missing for 8 subjects, representing 1100 patients receiving care.

Table 1. Estimated Number of Patients with HIV Participating in Clinical Trials of Medications or Research Studies and Number Who Ever Received Experimental Treatment.

In a multiple regression model with adjustment for characteristics of the patient, the type of health insurance, and attitudes about health care, both non-Hispanic black and Hispanic patients had significantly lower odds than non-Hispanic whites of participating in a medication trial. Patients in private HMOs participated less often than those with private fee-for-service insurance; those who were receiving care farther from the nearest clinical-trial center participated less often than those who were receiving care less than 1 mile (1.6 km) away from such a center; and men participated less often than women (Table 2). There was no difference between men and women in terms of the likelihood of receiving experimental treatments.



VARIABLE	PARTICIPATION IN AN HIV MEDICATION TRIAL OR STUDY AT FOLLOW-UP INTERVIEW	EVER HAVING RECEIVED EXPERIMENTAL TREATMENT
	adjusted odds ratio (95% CI)	
Race or ethnic group		
Non-Hispanic white	1.00	1.00
Non-Hispanic black	0.50 (0.28–0.91)	0.41 (0.32–0.54)
Hispanic	0.58 (0.37–0.93)	0.56 (0.41–0.78)
Other†	0.80 (0.35–1.82)	0.65 (0.29–1.44)
HIV risk category		
Man who has sex with men (or other risk category)	1.00	1.00
Injection drug user	1.22 (0.68–2.17)	1.02 (0.78–1.33)
Heterosexual	0.73 (0.42–1.27)	0.68 (0.49–0.95)
Sex		
Male	1.00	1.00
Female	1.40 (1.04–1.88)	0.98 (0.76–1.27)
Age		
18–34 yr	1.00	1.00
35–49 yr	0.88 (0.64–1.21)	1.11 (0.89–1.38)
≥50 yr	0.92 (0.57–1.51)	1.02 (0.67–1.55)
Level of education		
College graduate	1.00	1.00
Some college	0.71 (0.46–1.09)	0.71 (0.56–0.91)
High-school graduate	0.47 (0.28–0.81)	0.55 (0.41–0.74)
Some high school	0.58 (0.29–1.14)	0.42 (0.28–0.64)
Health insurance		
Private fee-for-service	1.00	1.00
Private HMO	0.43 (0.21–0.88)	0.75 (0.51–1.09)
Medicare	1.17 (0.69–1.98)	0.96 (0.62–1.48)
Medicaid	1.38 (0.67–2.82)	0.75 (0.46–1.21)
None	0.92 (0.53–1.61)	0.69 (0.43–1.13)
Distance to closest ACTG or CPCRA clinical-trial center‡		
0–1 mi	1.00	1.00
2–7 mi	0.50 (0.29–0.85)	0.65 (0.40–1.04)
8–74 mi	0.38 (0.18–0.78)	0.41 (0.26–0.64)
≥75 mi	0.61 (0.30–1.24)	0.50 (0.29–0.86)

No. of HIV patients cared for in the physician's practice		
≥500	1.00	1.00
100–499	1.88 (1.10–3.22)	1.68 (1.05–2.68)
10–99	0.62 (0.22–1.72)	0.64 (0.36–1.14)
1–9	0.81 (0.09–7.09)	2.91 (0.86–9.89)
Region		
Northeast	1.00	1.00
Midwest	1.60 (0.91–2.81)	1.63 (0.96–2.79)
South	0.77 (0.37–1.58)	1.39 (0.74–2.61)
West	2.56 (0.87–7.59)	1.58 (0.90–2.76)

Table 2. Factors Associated with Participating in a Clinical Trial or Study of HIV Medication and with Ever Having Received Experimental Treatment.

Patients who had positive attitudes toward antiretroviral medications and trust in their HIV care provider at base line had higher rates of subsequent enrollment in medication trials. However, neither patients' trust in their provider nor their desire for information or for involvement in making decisions about their care was independently associated with participation in trials, according to multivariate analyses (Table 3). Furthermore, neither removing variables related to attitudes in order to assess the effects of characteristics of the patient and of the type of health insurance alone nor removing variables related to health insurance in order to assess characteristics of the patient alone changed the size or significance of the effect of race or ethnic group or other patient-related variables on the likelihood of participation in a medication trial (data not shown).

ATTITUDE OR BELIEF	PATIENTS IN THE UNITED STATES RECEIVING HIV CARE AT BASE LINE	PATIENTS PARTICIPATING IN A MEDICATION TRIAL OR STUDY AT ANY INTERVIEW		ADJUSTED ODDS OF PARTICIPATING IN A MEDICATION TRIAL OR STUDY AT FOLLOW-UP INTERVIEW†
	weighted no.	%	P value	odds ratio (95% CI)
Are antiretrovirals worth taking?‡			<0.001	
Definitely	110,100	17±2		1.00
Probably	73,400	13±2		0.58 (0.40–0.82)
Probably not	20,900	8±2		0.64 (0.42–0.98)
Definitely not	20,500	11±3		0.55 (0.27–1.14)
Level of trust in the doctor or clinic			0.04	
High	112,000	16±2		1.00
Low	119,400	12±1		0.81 (0.58–1.12)
Level of desire for information about health and treatment			0.16	
High	130,900	15±2		1.00
Low	100,500	13±2		1.27 (0.78–2.05)
Level of desire for involvement in treatment decisions			0.07	
High	128,500	15±2		1.00
Low	102,900	12±2		1.14 (0.81–1.60)

*Results were weighted to represent the estimated population of patients with HIV receiving care in the United States. Plus–minus values are proportions ±SE. The levels of trust, of desire for information, and of desire for involvement in treatment decisions were determined on the basis of ratings on a Likert scale in response to two questions for each variable; responses were then dichotomized on the basis of the median score. HIV denotes human immunodeficiency virus, and CI confidence interval.

†The multivariate logistic-regression model was adjusted for differences in the stage of HIV disease (as assessed in terms of the nadir CD4+ lymphocyte count) and the sociodemographic variables listed in Table 2.

‡Data were missing for 78 subjects, representing 6500 patients receiving care.

Table 3. Health-Related Attitudes and Beliefs Associated with Participation in a Clinical Trial or Study of HIV Medication.

Changes in Participation Rates

The proportion of the patients participating in HIV research who were non-Hispanic blacks (20 percent at base line) did not increase between the HCSUS base line and follow-up, and non-Hispanic blacks were more likely than other patients to withdraw from or stop participating in trials during that time (Figure 2). Forty-six percent of all those who were enrolled in a trial at base line were enrolled in a trial at follow-up. Among those enrolled in a trial at base line, the rate of participation at follow-up was higher among non-Hispanic whites (53 percent) than among non-Hispanic blacks (25 percent, P=0.04), higher among those with a college education (65 percent) than among those with only a high-school education (39 percent, P<0.001), and higher among patients with private fee-for-service insurance (62 percent) than among uninsured patients (37 percent, P=0.05); the rates were similar among women (41 percent) and among men (47 percent, P=0.42).

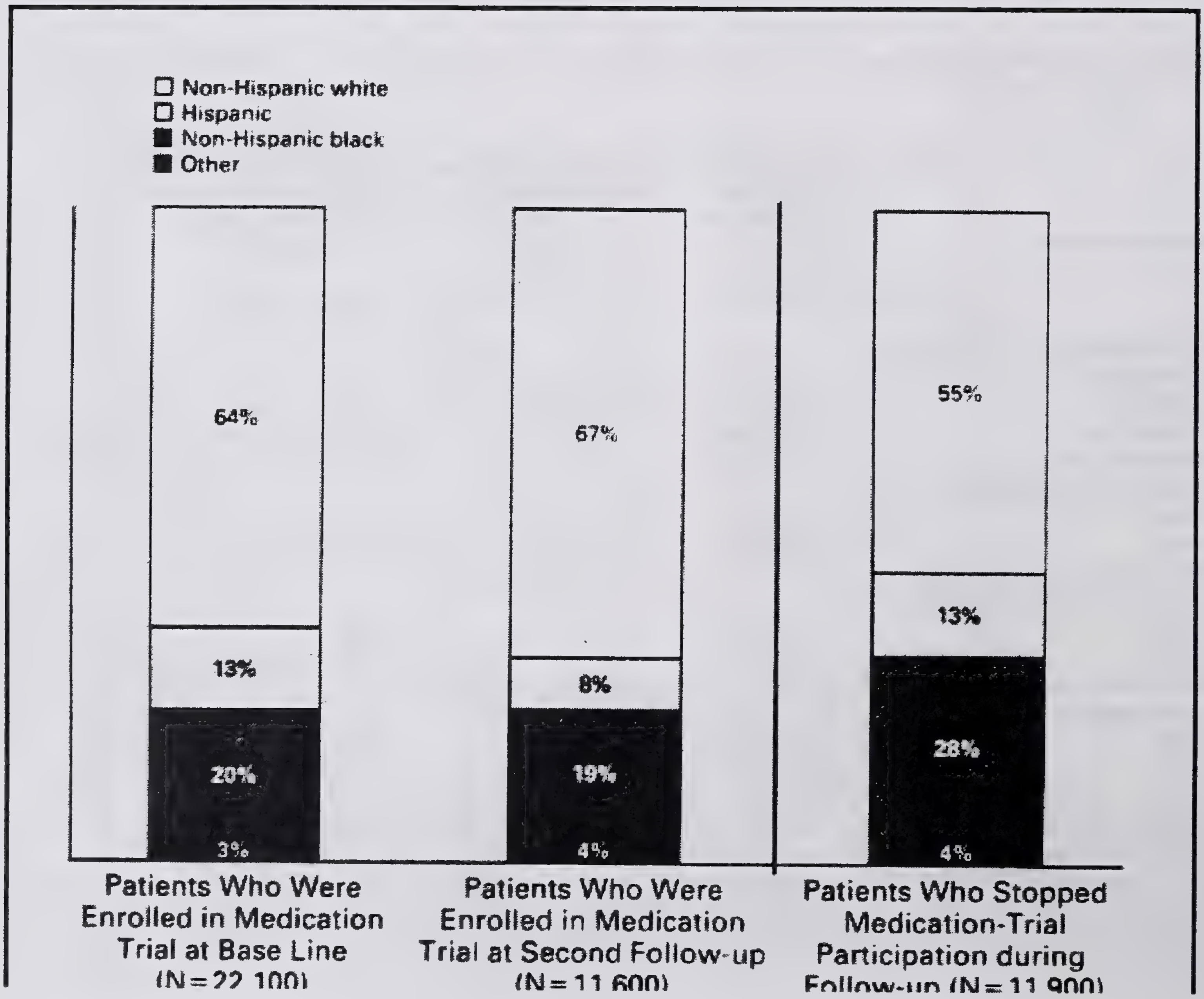


Figure 2. Changes in the Racial or Ethnic Mix of Trial Participants. Base-line interviews were conducted between January 1996 and April 1997, and second follow-up interviews were conducted between August 1997 and January 1998. Because of rounding, some percentages do not total 100. Numbers of patients are weighted.

Access to Experimental Medications

A total of 32 percent of the adults receiving care for HIV infection had tried to get experimental medication, and 24 percent had used an experimental medication at some time while receiving care. [11,20,21,36] Non-Hispanic white patients, men who had sex with men, patients with higher incomes, a higher level of education, or private health insurance, and those who received care closer to a clinical-trial center were all more likely to have received experimental medications at some time while receiving HIV care (Table 1).

In multivariate analyses with adjustment for the stage of disease and other characteristics of the patient and the type of health insurance, non-Hispanic whites, patients with higher levels of education, and patients receiving care closer to a clinical-trial center all remained more likely to have received experimental medications (Table 2). Most of the differences in participation rates were attributable to differences in the rates at which experimental medications were sought. However, even among those who sought experimental medications, non-Hispanic whites received them more often than non-Hispanic blacks (77 percent vs. 69 percent, P=0.008), and patients with private fee-for-service insurance received them more often than uninsured patients or those insured by private HMOs (83 percent, 69 percent, and 71 percent, respectively; P=0.03 for the three-way comparison).

When we adjusted for the severity of disease (as evaluated in terms of the CD4+ lymphocyte count), participants in research on medications were more likely than other patients to have received indicated prophylaxis against Pneumocystis carinii pneumonia (odds ratio, 1.8; 95 percent confidence interval, 1.4 to 2.3), prophylaxis against Mycobacterium avium complex (odds ratio, 1.6; 95 percent confidence interval, 1.1 to 2.3), and protease-inhibitor medications (odds ratio, 3.3; 95 percent confidence interval, 2.3 to 4.6). Research participants also had more frequent measurements of CD4+ lymphocytes recorded in their medical records than did nonparticipants (P=0.04), as well as more visits to the doctor (P=0.004).

Discussion

There are important reasons to be concerned about disparities among groups of patients with HIV in terms of enrollment in medication trials and expanded-access programs. Society and future patients benefit when participation in research is broad enough that results may be generalized to the patients receiving care who will eventually use the drugs. Current patients also benefit: although the efficacy of experimental treatments is unproven and the risk of harm is real, these treatments are often important and welcome alternatives for seriously ill patients who have few other options. Patients who have few social resources may also receive primary care, case management, and other resources by participating in research. Advocacy groups and federal legislators have emphasized the need for patients to have access to trials and investigational treatments. [37]

More HIV-infected patients than patients with other serious diseases do obtain experimental treatments. We estimate that 14 percent of HIV-infected adults receiving care in the United States participated in a medication trial during the study period; by comparison, enrollment in cooperative group trials of the National Cancer Institute during a similar period was estimated at only 4 percent among adults with cancer who were 20 to 49 years of age and 1.5 percent among those 50 years of age or older. [38] We also estimated that 24 percent of adult patients receiving care for HIV infection received experimental medications through a trial or an expanded-access program at some time. However, our data suggest that about 18,500 patients (8 percent of the patients receiving HIV care) had tried and failed to get experimental treatments.

Our findings confirm that there are disparities among racial or ethnic groups in the rate of study enrollment, as others have observed in selected populations of patients with HIV or inferred from the racial or ethnic composition of particular trial cohorts; moreover, these findings suggest that such disparities persisted up to four years after the National Institutes of Health (NIH) issued guidelines for increasing the enrollment of members of minority groups. These findings are especially striking in view of the fact that the HCSUS is a study limited to patients receiving care for HIV infection, so that imbalances among racial or ethnic groups in basic access to care did not contribute to the differences we found. The effects of race or ethnic group were seen even within socioeconomic strata, remained apparent after multivariate adjustment for the level of education, and seemed to be present in all aspects of access to research.

We found that fewer than half as many black patients as white patients attempt to obtain experimental HIV medications, suggesting that there is less awareness and a more widespread negative attitude about research in minority communities. Suspicion about research has long been recognized among black persons and may date back to past injustices such as the Tuskegee Syphilis Study and to beliefs within urban minority communities that HIV itself could be a government plot or experiment. [39,40] Black persons may interpret informed-consent procedures as "liability waivers" for researchers that do little to protect patients. [40,41] Innovative and culturally sensitive methods of communicating the benefits and risks of research to minority-group patients could be helpful, and consideration should be given to expanding such efforts. [42,43]

Previous research on differences among racial or ethnic groups in recruitment for clinical trials has produced varied results, possibly because of differences in study design or because of disease-specific, time-specific, or situation-specific factors. [16,18,38,44-46] Disproportionately few black persons participated in 50 drug studies performed in the mid-1980s, but blacks were overrepresented, as compared with other groups, in a large multicenter study of schizophrenia, [44,45] and no differences among racial or ethnic groups were seen in rates of participation in major cancer and heart-disease trials. [46] In the light of increasing evidence that sex differences in health and medicine may be more pervasive than previously imagined, it is encouraging to find that women were well represented in HIV-related trials. [18,47]

Errors could have influenced our results. Although the patients we approached were randomly selected, those who agreed to participate in the survey may have been more likely to enroll in clinical-research trials than those who did not participate. Concern about this issue led us to incorporate adjustments for those who did not respond to the survey into our analytic weights, but the adequacy of these adjustments is difficult to assess. Assessments of research participation based on the answers to interview questions could be inaccurate, but there is little reason to suspect that those interviewed would exaggerate or minimize their participation in research to conform to social pressures or that they would have difficulty recalling participation in studies. Moreover, we used a number of survey procedures, such as careful construction of the questions, scripted probes to clarify responses when necessary, central training of interviewers, and on-call backup, to minimize the risk of error. Furthermore, the validity of the results is supported by associations between self-reported participation in research and greater use of important HIV care services, such as CD4+ lymphocyte measurements and visits to the health care provider. These patterns are consistent with the receipt of protocol-driven care.

Outreach programs and efforts by providers to educate patients about research and investigational treatments could improve trust in researchers and boost enrollment. However, such programs may not eliminate disparities in access to experimental drugs, since certain groups, such as blacks, were less likely to receive experimental treatments for HIV infection even when they tried, and they had higher rates of withdrawal from studies after they had enrolled. In our study, characteristics of the practice providing the patient's HIV care, such as a higher number of patients with HIV treated on site and close proximity to an NIH-funded HIV trial center, were independently associated with enrollment in research and use of experimental medications. This finding suggests that we must examine critically such structural barriers as the entry criteria for trials, enrollment and tracking procedures, and the practical details of study-center operation, as well as the attitudes and practices of clinical researchers. [48]

New, innovative therapies for HIV have been successful in part because of impressive participation in the well-designed clinical research studies that have guided treatment and in expanded-access programs for persons with few other options. Nevertheless, as the demographic features of the epidemic have shifted toward patients with fewer resources, the disproportionately small number of disadvantaged patients who are enrolled in treatment trials or have early access to experimental therapies is of particular concern. The pace of therapeutic advances and the acceptance of new therapies in underserved communities may be slowed. Initiatives to increase access to and acceptance of clinical trials are needed for patients with HIV disease, as well as for patients with other conditions among whom participation in research is less common.

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but far less substantial toxicity may be due to other sources, such as tap water contaminated by lead pipes.

For the primary prevention of lead poisoning from paint, we recommend permanent abatement — that is, the complete removal or replacement of lead paint before a child lives in a home.[11,12] In contrast, "interim" measures, which were introduced for the short-term reduction of hazards associated with lead paint[11,13] and which involve scraping and painting over deteriorated surfaces and controlling household dust, have been claimed by some to save substantial cost; however, there is no evidence of savings in terms of net benefit over cost in the long-term prevention of childhood lead poisoning. Lead-painted surfaces in good condition rarely remain so. What was once intact lead-based paint is the source of all lead-bearing dust and paint chips. Therefore, it is the presence of lead paint on surfaces that defines the hazard, not the condition of surfaces containing lead paint.

Although succimer therapy resulted in lower blood lead levels, its failure to reverse neurocognitive deficits in the study by Rogan et al. confirms the need for collective and concerted efforts to prevent lead poisoning in children.

JOHN F. ROSEN, M.D.
PAUL MUSHAK, PH.D.
Children's Hospital at Montefiore
Bronx, NY 10467

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RACIAL DISPARITIES IN MEDICAL CARE

MANY studies have shown that black Americans are less likely than whites to receive a wide range of medical services, including potentially lifesaving surgical procedures.[1,2] Despite these data, which span two decades, there is little evidence that racial disparities in medical care or in measures of health have substantially diminished. Black Americans have an average life expectancy that is 6 years shorter than that of white Americans, and there has been little change in this disparity during the past 30 years.[3]

Why has the evidence on racial disparities failed to galvanize a response within the medical community? Four factors have contributed to the slow pace of change. First, much of the evidence has been based on administrative data, leading some clinicians to believe that racial disparities reflect unmeasured differences in clinical or socioeconomic factors. Second, clinicians may believe that whites are more likely than blacks to prefer intensive medical treatment or surgical therapy. Indeed, some research has suggested that there are such differences in preferences according to race, although the differences are small and probably cannot explain large racial differences in treatment.[4] Third, few studies have evaluated differences in clinical outcomes that may be directly related to disparities in the use of medical services or surgical procedures or have examined whether black Americans are less likely than whites to receive clinically important, needed services.[5-8] Fourth, even if the will to reduce racial disparities is strong, the pathways from intervention to improved quality of care have not been well charted.[9]

Despite these uncertainties, racial disparities in medical care are particularly troubling for at least two reasons: the possibility that they reflect discrimination or racial bias on the part of physicians and their potentially deleterious effects on health outcomes. The article by Chen et al.[10] in this issue of the *Journal* provides information relevant to both of these points and represents an advance in our understanding of racial disparities in medical care. Approximately 40,000 Medicare beneficiaries who were hospitalized in 1994 or 1995 with acute myocardial infarction were followed to assess whether they had undergone cardiac catheterization within 60 days after hospital admission and to determine their rates of death during the ensuing 3 years. White patients were significantly more likely than black patients to undergo cardiac catheterization. However, this racial difference in care did not vary according to whether the patient's attending physician was white (rate of catheterization, 45.7 percent for white patients vs. 38.4 percent for black patients) or black (49.6 percent vs. 38.2 percent, respectively), suggesting that overt racial prejudice did not account for racial differences in the rates of cardiac catheterization.

Racial bias is difficult to detect in surveys of physicians or medical records. Physicians may have various biases, but they often do not perceive them and would not report them as such. Thus, it is no surprise that previous studies have not directly documented bias. Instead, racial bias has always remained a possible explanation for residual racial differences in treatment, after other explanatory factors have been accounted for.

Of course, even if — as the findings of Chen et al. suggest — overt racial bias is unlikely to be a major explanation for differences in the rates of cardiac catheterization, both white and black physicians may have subtle biases that are based on other social factors and that influence their judgments about patients' suitability for procedures. For example, previous research has documented difficulties in communication about cardiac testing between physicians and patients of lower socioeconomic status,[11] and physicians report personal perceptions of less affluent or less well educated patients that are more negative than their perceptions of other patients.[12] Black patients are disproportionately represented in these socioeconomic groups.

Chen and colleagues also report that adjusted mortality rates over a three-year period in black patients were lower than or equivalent to those in white patients.[10] This study, however, was unable to assess whether blacks underwent fewer necessary or appropriate procedures that were likely to improve outcomes than whites.[13] In a study based on detailed clinical data from one academic medical center, the rate of underuse of coronary-artery bypass surgery was much greater among black patients than among white patients for whom this procedure was projected to prolong survival by one year or more.[5] Differences in treatment according to race explained about half the actual difference between blacks and whites in their adjusted five-year mortality rates. This study and others that have assessed the appropriate use of important medical procedures known to improve outcomes[6-8] or that have measured rates of use of several basic processes of care related to survival (such as physical examinations and diagnostic testing)[14,15] provide a compelling rationale for eliminating racial disparities in medical care that have important health consequences.

Given the widely documented pattern of racial differences in health care and some evidence about their causes and clinical effects, what steps should be taken to address these differences? Measuring differences in treatment according to race remains an important endeavor.[2] Documentation that blacks receive fewer services than whites may not be novel, but it is still necessary to gauge the effect of interventions to reduce racial disparities and to monitor whether the disparities are diminishing. We should also continue to clarify the clinical effects of racial disparities.[16] Unless differences in medical care according to race reflect the quality of care and meaningfully affect patients' survival or quality of life, the existence of racial disparities will remain of far greater interest to social scientists than to policy makers and physicians.

Our ultimate success in addressing racial disparities in health care will require that we adapt general approaches to behavioral change. Experts in quality improvement have emphasized the importance of redesigning systems of care instead of simply identifying individual doctors who provide inadequate care. The disparities found by Chen and colleagues between white and black patients, regardless of the race of their physicians, suggest that the health care system is less responsive to black patients than to white patients, and that systemic change will therefore be required. For example, information systems should be redesigned to provide medical groups with timely feedback about treatment decisions, referral rates, and patients' ratings of their care according to race, ethnic background, and socioeconomic status.[2] For chronically ill patients, nurses or social workers could serve as proactive care coordinators who identify financial, logistic, or informational barriers to optimal care for underserved patients and then help them arrange appropriate medical evaluations and treatments with their physicians. It may even be appropriate to draw on the principles of social marketing and establish campaigns with charismatic public figures or physicians to encourage underserved patients to be more assertive in seeking appropriate care and to encourage their physicians to be more responsive. Finally, strategies for improving care must be tailored to specific clinical situations, particularly in the case of difficult decisions about medical procedures, such as coronary revascularization or renal transplantation.

In 1998, the federal government adopted a goal of eliminating racial and ethnic disparities in health care by 2010 in six clinical areas, including the treatment of cardiovascular disease.[17] This is a laudable goal. It is unlikely that a single, predominant cause of racial disparities remains to be identified or remedied; instead, small-to-moderate changes in numerous aspects of care may yield moderate-to-large cumulative changes in treatment patterns and outcomes. Eliminating racial disparities in health care is thus a complicated and difficult task. We should get on with it.

ARNOLD M. EPSTEIN, M.D.
Harvard School of Public Health
Boston, MA 02115

JOHN Z. AYANIAN, M.D., M.P.P.
Harvard Medical School
Boston, MA 02115

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Special Article

RACIAL DIFFERENCES IN THE USE OF CARDIAC CATHETERIZATION AFTER ACUTE MYOCARDIAL INFARCTION

JERSEY CHEN, M.D., M.P.H., SAIF S. RATHORE, M.P.H., MARTHA J. RADFORD, M.D., YUN WANG, M.S., AND HARLAN M. KRUMHOLZ, M.D.

ABSTRACT

Background Several studies have reported that black patients are less likely than white patients to undergo cardiac catheterization after acute myocardial infarction. The role of the race of the physician in this pattern is unknown.

Methods We analyzed data from the Cooperative Cardiovascular Project, a study of Medicare beneficiaries hospitalized for acute myocardial infarction in 1994 and 1995, to evaluate whether differences between black patients and white patients in the use of cardiac catheterization within 60 days after acute myocardial infarction varied according to the race of their attending physician.

Results Our study cohort consisted of 35,676 white and 4039 black patients with acute myocardial infarction who were treated by 17,550 white and 588 black physicians. Black patients had lower rates of cardiac catheterization than white patients, regardless of whether their attending physician was white (rate of catheterization, 38.4 percent vs. 45.7 percent; $P<0.001$) or black (38.2 percent vs. 49.6 percent, $P<0.001$). We did not find a significant interaction between the race of the patients and the race of the physicians in the use of cardiac catheterization. The adjusted mortality rate among black patients was lower than or similar to that among white patients for up to three years after the infarction.

Conclusions Racial differences in the use of cardiac catheterization are similar among patients treated by white physicians and those treated by black physicians, suggesting that this pattern of care is independent of the race of the physician. (N Engl J Med 2001;344:1443-9.)

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NUMEROUS studies have reported that black patients with coronary artery disease are less likely than white patients to undergo cardiac catheterization.[1-9] Many aspects of the physician–patient relationship that may account for treatment decisions have been described.[10] Factors associated with a difference in race between physicians and patients, such as cross-cultural miscommunication,[11,12] lack of rapport or trust,[13,14] and reduced willingness on the part of the patient to undergo an intervention,[15] may lead to the use of fewer procedures among black patients. Alternatively, bias on the part of physicians — due to subconscious perceptions, incorrect assumptions regarding the preferences of patients, or overt discrimination — may contribute to racial differences in the use of cardiac catheterization.[16,17] However, whether racial differences in the use of cardiac catheterization vary according to the race of the physician is unknown.

In previous studies, it has been observed that patients treated by physicians of a race other than their own participated less in decision making[13] and may have been less willing to consider cardiac interventions than patients whose physicians were of the same race as themselves.[15] We sought to examine whether the race of the physician contributes to racial differences in the use of cardiac catheterization. We hypothesized that if racial differences in the use of cardiac catheterization were associated with the race of the physician, then differences between black patients and white patients in the rate of cardiac catheterization would vary according to the race of the physician. We analyzed data from patients in the national Cooperative Cardiovascular Project to assess whether differences in the rate of cardiac catheterization and in survival after acute myocardial infarction were related to differences between the race of physicians and the race of patients.

METHODS

Patients

We performed a retrospective analysis of data from the Cooperative Cardiovascular Project, a Health Care Financing Administration quality-improvement initiative for patients with acute myocardial infarction.[18] The Cooperative Cardiovascular Project consisted of data on 234,769 hospitalizations among Medicare patients on a fee-for-service basis in 1994 or 1995 and had a discharge diagnosis of acute myocardial infarction (code 410 of the *International Classification of Diseases, 9th Revision, Clinical Modification* [ICD-9-CM]).[19] Patients with the following characteristics were excluded from our study: age of less than 65 years (17,591 patients); absence of a clinically confirmed diagnosis of acute myo-

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From the Section of Cardiovascular Medicine, Department of Medicine (J.C., S.S.R., M.J.R., H.M.K.), and the Section of Chronic Disease Epidemiology, Department of Epidemiology and Public Health (H.M.K.), Yale University School of Medicine, and the Yale–New Haven Hospital Center for Outcomes Research and Evaluation (M.J.R., Y.W., H.M.K.) — both in New Haven, Conn.; and Qualidigm, Middletown, Conn. (M.J.R., Y.W., H.M.K.).

cardial infarction (defined as documentation in the patient's chart of either a serum creatine kinase MB fraction above 0.05, a serum lactate dehydrogenase level more than 1.5 times the upper limit of normal, with the level of isoenzyme 1 exceeding the level of isoenzyme 2, or at least two of the following three conditions: chest pain, a serum creatine kinase level more than double the upper limit of normal, or evidence of a new acute myocardial infarction on an electrocardiogram) (31,179); previous percutaneous transluminal coronary angioplasty or coronary-artery bypass graft surgery (43,143); concurrent terminal illness (4616); hospitalization after transfer from another acute care hospital (42,277); readmission (25,185); unavailability of Medicare Part A data at time of analysis (34,187); or hospitalization outside the 50 United States (1760). Patients whose data could not be linked with American Hospital Association data were also excluded (2363). Some patients met more than one of the exclusion criteria. Of the remaining 118,953 patients, the cohort we considered was limited to the 75,893 patients in hospitals that had admitted at least 1 black patient with acute myocardial infarction in the Cooperative Cardiovascular Project during the study period.

Data on physicians were successfully matched for 73,846 of these 75,893 patients (97.3 percent), although data on the physician's race were not available for 24,452 of the 75,893 patients (32 percent). Patients with cardiovascular surgeons as attending physicians (1806 patients) were excluded because many of them were probably undergoing elective coronary-artery bypass graft surgery. The following patients were also excluded: patients whose race could not be confirmed as either white or black (2324), and patients who were treated by physicians who were neither white nor black (9106). Some patients met more than one of these exclusion criteria.

Dependent Variables

We evaluated Medicare Part A billing records for the use of cardiac catheterization (procedure codes 37.22, 37.23, and 88.53 through 88.57 of ICD-9-CM) within 60 days after admission with acute myocardial infarction. We ascertained death within three years after admission with acute myocardial infarction by supplementing information on vital status in the Cooperative Cardiovascular Project with data from the Death Master File of the Social Security Administration.[20]

Independent Variables

Race of the Patients and Physicians

The race of the patients in the Cooperative Cardiovascular Project was abstracted from medical records. The race of the attending physicians was identified with use of their unique physician identification numbers as recorded in Medicare Part A claims. The attending physician is regarded as "the clinician who is primarily and largely responsible for the care of the patient from the beginning of the hospital episode."[21] We linked the identification numbers of the attending physicians with the Physician Masterfile of the American Medical Association. The Physician Masterfile is a comprehensive, validated data base of information on physicians' characteristics,[22] collected from medical school matriculation forms, surveys of physicians, and residency training programs (Havlicek PL: personal communication).

Other Independent Variables

Because the severity of disease and the presence of coexisting illnesses influence the decision to use cardiac catheterization, we adjusted for the following predictive variables (based on published studies[23-26]) and clinically relevant factors: age; sex; Killip class at the time of admission; left ventricular ejection fraction; systolic blood pressure; heart rate; anatomical site of the acute myocardial infarction; presence or absence of a history of previous acute myocardial infarction or congestive heart failure; current smoking status; presence or absence of hypertension, diabetes mellitus, stroke, peripheral vascular disease, or renal dysfunction (blood urea nitrogen above 40 mg per deciliter [14 mmol per liter] or serum creatinine level above 2.0 mg per deciliter [177 μmol per liter]); and use or nonuse of thrombolytic therapy. We also adjusted for several nonclinical factors: characteristics of the hospitals, according to the American Hospital Association 1994 survey of hospitals (teaching status, ownership, and availability of on-site facilities for cardiac procedures)[27]; characteristics of the physicians, according to the American Medical Association Physician Masterfile (specialty, sex, decade of graduation, country of medical school, employment type, and type of training [osteopathic or allopathic]); and number of the physician's patients enrolled in the Cooperative Cardiovascular Project. Hospital volume (estimated from Medicare Part A data) and patients' income and education level (from 1990 U.S. Census data[28]) were classified into quintiles.

The survival analyses included the presence or absence of the following additional factors: inability to walk, urinary incontinence, dementia, admission from a nursing home, chronic obstructive pulmonary disease, liver disease, infection with the human immunodeficiency virus or other immunologic compromise, trauma within the previous month, a serum albumin level below 3 g per deciliter, a hematocrit below 30 percent, and use of aspirin, beta-blockers or angiotensin-converting–enzyme inhibitors during hospitalization or prescribed at discharge. Dummy variables indicating missing values were included in the multivariate analyses.

Statistical Analysis

Differences in the characteristics of the patients, the rate of cardiac catheterization, and mortality were assessed by means of chi-square tests for categorical variables and analysis of variance for continuous variables. We examined whether racial differences in the rate of cardiac catheterization or in survival persisted after adjustment for differences in the characteristics of the patients, the physicians, and the hospitals through a series of multivariate logistic-regression models. The effect of the race of the physician on differences between black patients and white patients in the use of cardiac catheterization was examined with the use of models incorporating interaction terms. We transformed odds ratios to relative risks by the method of Zhang and Yu.[29] We used Cox proportional-hazards regression models to assess the relative risks of death. All the regression models incorporated Huber–White robust standard errors, adjusted for clustering according to physician.[30] We used Stata statistical software (version 6.0, Stata, College Station, Tex.) to conduct the analyses.

RESULTS

Patients

Our cohort consisted of 35,676 white and 4039 black Medicare beneficiaries who were treated for acute myocardial infarction by 17,550 white physicians and 588 black physicians. The mean (±SD) age of the patients was 77±7.6 years (range, 65 to 108). Blacks represented 9 percent of the patients treated by white physicians and 53 percent of the patients treated by black physicians. Black patients were more likely to have hypertension, diabetes mellitus, renal dysfunction, previous heart failure, stroke, or peripheral vascular disease than white patients, regardless of the race of their physicians (Table 1). Other clinical characteristics of the two groups of patients were generally similar, whether they were treated by white or black physicians. Black patients were less likely to have board-certified cardiologists as attending physicians, were more likely to be treated in public or teaching hospitals, and on average lived in neighborhoods with lower levels of income and education than white patients, regardless of the race of their physicians.

TABLE 1. CHARACTERISTICS OF THE PATIENTS.*

CHARACTERISTIC	WHITE PHYSICIANS		BLACK PHYSICIANS	
	WHITE PATIENTS (N=35,176)	BLACK PATIENTS (N=3476)	WHITE PATIENTS (N=500)	BLACK PATIENTS (N=563)
Age (yr)	77.3±7.6	75.9±7.6†	76.6±7.3‡	76.1±7.5
Female sex (%)	47.5	41.2†	50.2	35.0§¶
Clinical history (%)				
Hypertension	60.4	77.9†	62.2	82.1§¶
Diabetes mellitus	28.7	41.2†	29.4	42.5§
Previous myocardial infarction	23.8	25.1	21.2	22.7
Previous heart failure	20.8	25.5†	19.6	27.5§
Current smoker	14.7	18.3†	18.2‡	17.9
Previous stroke	13.5	18.5†	11.4	18.5§
Peripheral vascular disease	10.1	11.6†	10.4	13.3
Characteristics on admission (%)				
Systolic blood pressure <100 mm Hg	7.2	7.0	9.2	8.0
Pulse >100 beats/min	26.6	29.3†	27.0	31.3
Renal dysfunction	11.8	20.9†	11.6	18.7§
Site of infarction				
Anterior	47.9	47.1	46.8	48.1
Inferior	46.9	44.1†	47.6	43.2
Left ventricular ejection fraction				
≥55%	13.1	13.0	15.4	13.5
40–54%	32.5	29.6†	27.0‡	30.7
20–39%	19.9	19.6	22.4	21.0
<20%	1.7	2.2†	1.8	2.8
Unknown	32.8	35.7†	33.4	32.0
Medications used during hospitalization or at discharge (%)				
Aspirin	80.9	79.8	77.2‡	75.7¶
Beta-blockers	47.8	43.8†	47.6	39.4§
Thrombolytic agents	18.3	13.5†	22.0‡	12.8§
Angiotensin-converting–enzyme inhibitors	38.1	43.1†	35.4	41.9§
Specialty of attending physician (%)				
Internal medicine	24.2	21.9†	26.6	24.2
Cardiology	27.2	23.9†	30.8	12.3§¶
Other internal-medicine subspecialty	11.0	13.5†	7.0‡	7.1¶
Family practice	15.4	16.3	12.2	14.0
Characteristics of hospital (%)				
Cardiac catheterization available	70.9	66.6†	63.4	68.2§
Teaching	41.7	46.5†	31.8‡	49.2§
Public	11.0	21.0†	10.2	19.7§
Private, not-for-profit	79.8	69.0†	80.0	70.7§
Socioeconomic characteristics				
Annual household income ($)	31,738±11,851	23,697±9,308†	28,571±9,575‡	22,953±8,791§
Population with at least a high-school diploma (%)	50.1	41.1†	47.0‡	40.5§

*Plus–minus values are means ±SD.

†$P<0.05$ for the comparison between black patients treated by white physicians and white patients treated by white physicians.

‡$P<0.05$ for the comparison between white patients treated by black physicians and white patients treated by white physicians.

§$P<0.05$ for the comparison between black patients treated by black physicians and white patients treated by black physicians.

¶$P<0.05$ for the comparison between black patients treated by black physicians and black patients treated by white physicians.

Use of Cardiac Catheterization

We found that black patients were significantly less likely than white patients to undergo cardiac catheterization within 60 days after admission, regardless of whether their attending physicians were white or black ($P<0.001$ for both comparisons) (Table 2). The rate of cardiac catheterization among white patients did not differ significantly according to whether their physicians were white or black (45.7 percent and 49.6 percent, respectively; $P=0.08$). Similarly, the rate of cardiac catheterization among black patients did not differ significantly according to whether their physicians were white or black (38.4 percent and 38.2 percent, respectively; $P=0.94$).

Table 2. Rate of Use of Cardiac Catheterization within 60 Days after Acute Myocardial Infarction among Black Patients and White Patients, According to the Race of Their Physicians.*

Rate	White Physicians		Black Physicians	
	white patients (n=35,176)	black patients (n=3476)	white patients (n=500)	black patients (n=563)
	percent (95 percent confidence interval)			
Unadjusted	45.7	38.4†	49.6	38.2†
Adjusted	45.7‡	32.9 (30.1–36.1)§	53.4 (43.4–65.8)	36.5 (29.2–45.2)¶

*In the adjusted analyses, adjustments were made for the characteristics of the patients, the physicians, and the hospitals. There were no significant differences in the rates of cardiac catheterization among either the white patients or the black patients according to the race of their physicians.

†P<0.001 for the comparison between black patients and white patients, regardless of the race of their physician.

‡These patients served as the reference group.

§P<0.001 for the comparison between black patients treated by white physicians and white patients treated by white physicians.

¶P=0.04 for the comparison between black patients treated by black physicians and white patients treated by black physicians.

In analyses that adjusted for the characteristics of the patients, the physicians, and the hospitals, black patients remained less likely to undergo cardiac catheterization than white patients treated by white doctors, regardless of the race of the black patients' attending physicians (Table 2). The difference between white patients and black patients in the adjusted rates of cardiac catheterization was 12.8 percentage points (45.7 percent and 32.9 percent, respectively) among those treated by white doctors and 16.9 percentage points (53.4 percent and 36.5 percent) among those treated by black doctors. In multivariate analyses of the use of cardiac catheterization, we did not find a significant interaction between the patient's race and the physician's race (P=0.73), indicating that black patients treated by black physicians did not undergo cardiac catheterization at a different rate from black patients treated by white physicians.

Mortality

Unadjusted 30-day mortality rates were lower among black patients than among white patients, regardless of the race of their attending physicians (Table 3). By the end of three years, unadjusted mortality rates were higher among black patients than among white patients, regardless of the race of their physicians. In multivariate analyses, however, 30-day mortality rates were significantly lower among black patients — both those treated by white physicians and those treated by black physicians — than among white patients treated by white physicians (Table 4). Three-year adjusted mortality rates among black patients treated by white physicians were also lower than the rates among white patients treated by white physicians; the same was true of black patients treated by black physicians as compared with white patients treated by white physicians. The results were consistent when analyses were limited either to patients who underwent cardiac catheterization or to those who did not undergo the procedure.

Table 3. Unadjusted Mortality among Black Patients and White Patients, According to the Race of Their Physicians.*

Follow-up	White Physicians		Black Physicians	
	white patients	black patients	white patients	black patients
	percent			
30 days	19.4	17.3†	20.4	18.5
1 yr	32.8	33.1	31.2	36.8
2 yr	40.0	41.1	38.2	44.9‡
3 yr	46.0	48.5†	43.2	52.4‡

*There were no significant differences in the mortality rates among either the white patients or the black patients according to the race of their physicians.

†P<0.05 for the comparison between black patients treated by white physicians and white patients treated by white physicians.

‡P<0.05 for the comparison between black patients treated by black physicians and white patients treated by black physicians.

DISCUSSION

Our findings are consistent with those of previous studies that reported differences between white and

TABLE 4. ADJUSTED MORTALITY AMONG BLACK PATIENTS AND WHITE PATIENTS, ACCORDING TO THE RACE OF THEIR PHYSICIANS.*

FOLLOW-UP	WHITE PHYSICIANS		BLACK PHYSICIANS	
	WHITE PATIENTS	BLACK PATIENTS	WHITE PATIENTS	BLACK PATIENTS
	hazard ratio (95% CI)			
30 Days	1.00	0.78 (0.72–0.86)	0.99 (0.79–1.25)	0.74 (0.59–0.92)
1 Yr	1.00	0.87 (0.81–0.93)	0.91 (0.76–1.08)	0.88 (0.76–1.03)
2 Yr	1.00	0.87 (0.82–0.93)	0.91 (0.78–1.06)	0.89 (0.77–1.02)
3 Yr	1.00	0.89 (0.84–0.95)	0.90 (0.79–1.04)	0.91 (0.80–1.03)

*Adjustments were made for the characteristics of the patients, the physicians, and the hospitals. CI denotes confidence interval. White patients treated by white physicians served as the reference group.

black Medicare beneficiaries[7] and other white and black populations[1-6,8,9] in the rate of cardiac catheterization. In addition, our study found that black patients underwent cardiac catheterization less frequently after acute myocardial infarction than white patients, regardless of the race of their physicians. The absence of an interaction between the race of the patient and the race of the physician suggests that racial discordance between the patient and the physician does not explain differences between black patients and white patients in the use of cardiac catheterization.

What factors could potentially explain the lower rate of use of cardiac catheterization in black patients, regardless of the physician's race? Differences in clinical characteristics among races are one possible explanation. Black patients are less likely than white patients to describe typical chest pain after acute myocardial infarction[12,31] and are more likely to have nondiagnostic electrocardiograms at the time of presentation.[6] These factors might reduce the likelihood that black patients will undergo cardiac catheterization, although they would be expected to be less important once the diagnosis of acute myocardial infarction has been confirmed.

It is possible that black patients may be less willing than white patients to undergo cardiac procedures because of different thresholds for procedure-related risks, different levels of trust in the medical system, or different degrees of familiarity with these treatments.[14,15] In previous studies, black patients were more likely to refuse to undergo cardiac procedures than white patients.[32] Conversely, white patients may be more aggressive in seeking such procedures. Other interactions between patients and physicians that are related to race may also play a part in ways that have not yet been defined.[13]

Unmeasured or unmeasurable differences in socioeconomic factors may also have contributed to the lower rate of cardiac procedures among blacks, regardless of the race of their physicians. Although we adjusted for income and education according to local U.S. Census data, we cannot exclude the possibility of residual confounding due to heterogeneity of these factors within neighborhoods. Furthermore, although Medicare paid the hospital bills of all the patients in our study, there still may have been differences in their ability to pay for care. For example, our study was unable to assess the effects of supplemental "Medigap" insurance, which pays for outpatient visits, medications, or out-of-pocket expenses, including deductibles and copayments. Because nonwhite Medicare beneficiaries are less likely to have supplemental insurance than white beneficiaries,[33] the prospect of incurring substantial out-of-pocket costs may have been a strong disincentive to undergoing cardiac catheterization. Important social factors, such as the availability of family support, may also have an important role. For example, it has been reported that patients who are married may be more likely to undergo a cardiac procedure than those who are not married,[1] and according to the same study, blacks are less likely to be married than whites.

Whether differences in the rate of cardiac procedures between black patients and white patients are associated with differences in outcomes is uncertain. Several studies found that black patients have poorer long-term survival after acute myocardial infarction than white patients.[34,35] Other studies showed that although blacks underwent fewer cardiac procedures, their survival after hospitalization for acute myocardial infarction was equivalent to or better than that of whites.[1,4,6,7] We found that 30-day mortality rates were lower in blacks than in whites, and this trend, though it diminished, persisted up to three years of follow-up.

Differences in the unmeasured clinical characteristics of patients of different races are one potential reason why blacks may have had a lower rate of death after acute myocardial infarction than white patients.

Nonwhite race is associated with failure to hospitalize for acute myocardial infarction,[36] and if black patients with more severe infarctions died before admission, the proportion of hospitalized black patients with less severe infarctions would be greater than that of hospitalized white patients.[37] Studies showing that blacks have higher rates of out-of-hospital death from infarction[38] and cardiac arrest[39] are consistent with this hypothesis. Although it is not clear whether the differences in mortality according to race in our study were due to differences in the clinical characteristics or medical treatment of the patients, our findings do not support the hypothesis that the lower rate of use of cardiac catheterization in black patients is associated with worse survival.

Given the design of our study, we were unable to assess whether cardiac procedures were underused, appropriately used, or overused in either black patients or white patients. We were also unable to examine potential interactions between the patients and the specialists consulted by attending physicians who were not cardiologists. However, the decision to initiate consideration for catheterization by requesting consultation with a cardiac specialist or by transferring the patient to an outside hospital with a cardiac catheterization laboratory is typically the responsibility of the attending physician. We were unable to evaluate the decision to refer a patient for catheterization because we examined only the actual use of the procedure. Finally, we cannot rule out the possibility that institutional factors and attitudes common to black and white physicians contribute to lower rates of cardiac catheterization in black patients than in white patients. Despite these limitations, our findings indicate that there is no interaction between the race of the physician and the race of the patient in the use of cardiac catheterization. The observation that racial differences in the use of cardiac catheterization are similar among patients treated by black physicians and white physicians suggests that racial discordance between patients and physicians does not explain racial differences in the use of this procedure.

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The Effect of Patients' Preferences on Racial Differences in Access to Renal Transplantation

[Special Articles]

Ayanian, John Z.; Cleary, Paul D.; Weissman, Joel S.; Epstein, Arnold M.

From the Department of Medicine, Division of General Medicine and Primary Care, Section on Health Services and Policy Research, Brigham and Women's Hospital and Harvard Medical School (J.Z.A., A.M.E.); the Department of Health Care Policy, Harvard Medical School (J.Z.A., P.D.C., J.S.W.); the Institute for Health Policy, Massachusetts General Hospital (J.S.W.); and the Department of Health Policy and Management, Harvard School of Public Health (A.M.E.) - all in Boston. Address reprint requests to Dr. Ayanian at the Department of Health Care Policy, Harvard Medical School, 180 Longwood Ave., Boston, MA 02115, or at ayanian@hcp.med.harvard.edu.

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Abstract

Background: In the United States, black patients undergo renal transplantation less often than white patients, but few studies have directly assessed the association between race and patients' preferences with respect to transplantation.

Methods: To assess preferences with respect to transplantation and experiences with medical care, we interviewed 1392 (82.9 percent) of 1679 eligible patients with end-stage renal disease (age range, 18 to 54 years) approximately 10 months after they had begun maintenance treatment with dialysis. Participants were selected from a stratified random sample of patients undergoing dialysis in four regions of the United States (Alabama, southern California, Michigan, and the mid-Atlantic region of Maryland, Virginia, and the District of Columbia) in 1996 and 1997. Patients were followed until March 1999.

Results: The interviews were conducted with 384 black women, 354 white women, 337 black men, and 317 white men. Black patients were less likely than white patients to want a transplant (76.3 percent of black women reported such a preference, vs. 79.3 percent of white women, and 80.7 percent of black men vs. 85.5 percent of white men), and they were less likely to be very certain about this preference (58.3 percent vs. 65.3 percent and 64.1 percent vs. 75.7 percent, respectively; $P<0.01$ for each comparison with both sexes combined). However, much larger differences were evident in rates of referral for evaluation at a transplantation center (50.4 percent for black women vs. 70.5 percent for white women, and 53.9 percent for black men vs. 76.2 percent for white men; $P<0.001$ for each comparison) and placement on a waiting list or transplantation within 18 months after the start of dialysis therapy (31.3 percent for black women vs. 56.5 percent for white women, and 35.3 percent for black men vs. 60.6 percent for white men; $P<0.001$). These racial differences remained significant after adjustment for patients' preferences and expectations about transplantation, sociodemographic characteristics, the type of dialysis facility, perceptions of care, health status, the cause of renal failure, and the presence or absence of coexisting illnesses.

Conclusions: In the United States, the preferences and expectations with respect to renal transplantation among patients with end-stage renal disease differ according to race. These differences, however, explain only a small fraction of the substantial racial differences in access to transplantation. Physicians should ensure that black patients who desire renal transplantation are fully informed about it and are referred for evaluation. (N Engl J Med 1999;341:1661-9.)

Racial differences in access to effective medical procedures are a persistent problem in the United States. [1-6] Black patients are less likely than white patients to undergo renal transplantation, [7-12] coronary-artery bypass surgery and angioplasty, [13-16] carotid endarterectomy, [17] peripheral vascular surgery, [18] total knee and hip arthroplasty, [5,19] cataract surgery, [2] sigmoidoscopy, [2] and screening mammography. [2,20] Although these differences have been documented repeatedly, health care providers and policy makers have been slow to improve black patients' access to medical procedures, possibly in part because the reasons for the racial differences are unclear. [21] Racial bias is one possible explanation, but some have speculated that patients' preferences might explain racial differences in care. [22] Despite the importance of this issue, only a few studies have examined the association between race and patients' preferences with regard to major procedures [23-27]; these studies have been limited by small numbers of patients and indirect measures of preferences.

Renal transplantation is a useful model for the direct assessment of patients' preferences. In 1996, more than 70,000 Americans began treatment for end-stage renal disease (ESRD), and nearly 12,000 received renal transplants. [28] Since people with ESRD require life-sustaining dialysis or transplantation, almost all potential candidates for transplantation, unlike candidates for most other major medical procedures, can be reliably identified and located. Transplantation is an attractive treatment option because it improves the quality of life and is less costly than lifelong dialysis. [29-31]

Despite these benefits, black patients are much less likely than white patients to be evaluated for renal transplantation and placed on a waiting list for a transplant, [9-11] and these differences have not been attributable to clinical factors, such as coexisting conditions or functional status. [10-12] To determine whether racial differences in access to transplantation are explained by patients' preferences, we interviewed patients with ESRD in four regions of the United States.

Methods

Study Sample

We studied patients with newly diagnosed ESRD who resided in Alabama, southern California, Michigan, or the mid-Atlantic region (Maryland, Virginia, and the District of Columbia), in collaboration with the ESRD Networks serving these four geographically diverse areas (Network 8, the Southern California Renal Disease Council, the Renal Network of the Upper Midwest, and the Mid-Atlantic Renal Coalition, respectively). These organizations are funded by the Health Care Financing Administration to monitor and improve the quality of care provided to patients with

ESRD. The study protocol was approved by the Human Studies Committee of Harvard Medical School and by the Health Care Financing Administration.

Each renal network identified all patients between the ages of 18 and 54 years who had begun to receive maintenance treatment with dialysis during the period from May 1996 through June 1997 (through September 1997 in Alabama). We focused on this age group because relatively few children undergo dialysis, and they are often treated in specialized units, and because adults over the age of 54 years are much more likely than younger adults to have coexisting illnesses that preclude transplantation. [12] We selected a stratified random sample of black women, black men, white women, and white men within each region, for a total of 1933 patients. We excluded 254 patients for the following reasons: they had died (100 patients) or moved out of their region (25) within nine months after starting dialysis; they had speech, hearing, or cognitive impairments that precluded an interview (51); they did not speak English (31); they had discontinued dialysis or could not be located (19); they had undergone dialysis before May 1996 or at more than three facilities (14); they were incarcerated (11); or they lacked a Social Security number (3).

Data Collection

We interviewed patients approximately 10 months after they had started dialysis therapy, allowing sufficient time for them to become accustomed to dialysis, discuss transplantation with their physicians, and undergo evaluation for a transplant, if desired. Patients were sent a letter from the Health Care Financing Administration describing the voluntary nature of our survey, followed by our letter inviting them to participate and offering a $20 stipend for completing the interview. Trained interviewers (Gordon Research Services, Orono, Me.) then made at least 10 attempts over a period of four weeks to interview patients by telephone at home.

We asked all patients whether they had received a kidney transplant. For patients who had not received a transplant, we asked the following questions: "Do you want to have a kidney transplant?" "How certain are you about this decision?" "Have you ever been referred to a transplant center to be examined and tested to see if it is appropriate for you to go on a transplant waiting list?" We also asked what effects the patients expected transplantation would have (as compared with dialysis) on their quality of life and survival.

To assess patients' perceptions of their medical care, we asked whether their primary nephrologist provided as much information as they desired, to what extent they agreed with that doctor about medical decisions, and to what extent they trusted that doctor's judgment. [32] We also asked whether a doctor had recommended transplantation or had discussed the possibility of receiving a kidney from a family member and whether they believed that they had received worse medical care than other patients in the previous six months because of their race, income, or sex.

Respondents rated their overall health during the most recent month on dialysis from 0 ("the poorest health a person can be in") to 100 ("the best health possible for a person of your age who has no major health problems"). Other dimensions of health status during the most recent month on dialysis (converted to a similar 100-point range) included energy (four items), emotional well-being (five items), physical activity (two items), social activity (one item), and the burden of kidney disease on daily life (nine items). [33] We also asked patients about their education, income, marital status, employment status, automobile ownership, medical insurance, and family history of kidney disease, as well as whether a family member was willing to donate a kidney to them.

We obtained data from the renal networks and the United Network for Organ Sharing on patients who had received a renal transplant or been placed on a waiting list as of March 1999; we were thus able to assess these outcomes 18 months after the start of dialysis therapy for all patients. Data on the type of dialysis facility (for-profit, not-for-profit, or government) were obtained from the Health Care Financing Administration. Renal-network staff also reviewed the medical records of 1169 surveyed patients whose records could be obtained (84.2 percent of black patients and 83.8 percent of white patients) to collect data on coexisting illnesses (coronary heart disease, congestive heart failure, peripheral vascular disease, chronic lung disease, and cancer) and referrals for evaluation at a transplantation center.

Statistical Analysis

We compared the characteristics of respondents and nonrespondents with the use of administrative data from the renal networks. Among respondents, we compared the socioeconomic and clinical characteristics of black and white patients with stratification according to sex, because prior studies have suggested that there are sex differences in access to renal transplantation. [7,10-12] We used Student's t-test to compare continuous variables and Pearson's chi-square test to compare categorical variables, and we report two-tailed P values for all descriptive tests.

Among surveyed patients, we analyzed patients' preferences for transplantation and two primary measures of access to transplantation: whether patients reported having been referred for evaluation at a transplantation center and whether they had been placed on a waiting list or had received a transplant within 18 months after the start of dialysis. We also compared these measures within each region and among respondents who wanted a transplant and those who were "very certain" about this preference. In a secondary analysis of the 1169 patients whose medical records were available, we reclassified 64 patients (23 black women, 12 white women, 18 black men, and 11 white men) who reported that they had not been referred for evaluation but whose medical records showed evidence of a referral. In another secondary analysis, we compared waiting-list rates according to race after excluding the 56 patients (6 black women, 22 white women, 3 black men, and 25 white men) who received transplants from living donors and were not placed on a waiting list.

We used multiple logistic regression to estimate the adjusted relative odds of two outcomes for black women, white women, and black men as compared with white men: referral for evaluation at a transplantation center and placement on a waiting list for a transplant or receipt of a transplant within 18 months after the start of dialysis therapy. In a series of models, we controlled for numerous factors that might account for racial differences in access to renal transplantation, including patients' preferences (wanting a transplant and being very certain about wanting it), expectations about transplantation (quality of life and survival), perceptions of care (views of the primary nephrologist and discrimination within the previous six months), sociodemographic characteristics (region, age, education, income, health insurance, employment status, marital status, and automobile ownership), type of dialysis facility, [34] primary cause of renal failure, health status (overall health and the five aspects noted above), and the five coexisting illnesses specified above. Using white men as the reference group, we converted these adjusted odds ratios to absolute probabilities, [35] which we report with 95 percent confidence intervals. This method of adjustment results in confidence intervals for all estimated probabilities except those in the reference group.

Results

Characteristics of the Patients

Of 1679 eligible patients, 1392 were interviewed (response rate, 82.9 percent), including 384 black women (82.8 percent of eligible black women), 354 white women (85.7 percent of eligible white women), 337 black men (81.2 percent of eligible black men), and 317 white men (81.9 percent of eligible white men) (P=0.33). Respondents and nonrespondents did not differ significantly according to age, region, rural or urban residence, body-mass index, primary cause of renal failure, or type of dialysis (P>0.12 for all comparisons). The median interval from the initiation of dialysis therapy to the interview was 10.2 months for black women, 9.8 months for white women, 9.4 months for black men, and 9.9 months for white men. Ten black women (2.6 percent), 48 white women (13.6 percent), 15 black men (4.5 percent), and 52 white men (16.4 percent) had received kidney transplants during this period (P=0.001), most commonly from living donors (9, 28, 8, and 32 patients, respectively).

Black and white respondents were similar with respect to the region, age, and presence or absence of a history of kidney disease in members of the immediate family (Table 1). However, significantly fewer black women and men than white women and men had graduated from high school or college, had relatively high incomes, were married or employed, owned an automobile, had private health insurance, or had diabetes as the primary cause of ESRD. Black women were more likely than white women to be undergoing dialysis in for-profit facilities. Black patients reported better overall health and higher energy levels during dialysis therapy than white patients but reported similar levels of emotional well-being, physical activity, and social activity and a similar burden of kidney disease in daily life. White patients were more likely than black patients to have coronary artery disease, and white men were more likely than black men to have peripheral vascular disease.

CHARACTERISTIC	BLACK WOMEN (N=384)	WHITE WOMEN (N=354)	P VALUE†	BLACK MEN (N=337)	WHITE MEN (N=317)	P VALUE†
Region (%)			0.99			0.30
Alabama	17.2	17.2		18.7	18.9	
Michigan	29.7	30.5		24.6	29.3	
Southern California	20.8	21.2		20.5	22.1	
Mid-Atlantic region	32.3	31.1		36.2	29.7	
Mean age (yr)	42.0	42.7	0.28	41.7	41.6	0.87
Education (%)			0.001			0.001
College graduate	9.9	13.6		12.5	18.3	
High-school graduate	64.1	68.8		63.2	65.6	
Neither	26.0	17.6		24.3	16.1	
Annual income (%)			0.001			0.001
≥$60,000	4.4	17.8		10.1	21.8	
$40,000–$59,999	10.9	16.9		9.2	15.5	
$20,000–$39,999	21.6	26.6		26.4	24.9	
$12,000–$19,999	20.1	16.7		19.6	17.7	
<$12,000	28.7	11.6		23.1	13.9	
Unknown	14.3	10.4		11.6	6.3	
Married (%)	32.3	62.2	0.001	45.4	56.8	0.001
Employed (%)	13.5	24.6	0.001	18.4	32.2	0.001
Automobile owner (%)	65.6	91.2	0.001	82.8	92.7	0.001
Private health insurance (%)‡	38.5	65.5	0.001	38.6	62.8	0.001
History of kidney disease in immediate family (%)	22.9	22.4	0.74	21.1	17.0	0.42
Primary cause of ESRD (%)			0.001			0.001
Diabetes mellitus	37.0	46.0		25.8	44.2	
Hypertension	35.9	7.1		41.5	10.1	
Glomerulonephritis	9.9	13.0		14.0	20.8	
Other	17.1	33.9		18.7	24.9	
Type of dialysis facility (%)			0.04			0.72
For-profit	68.0	61.3		66.2	66.6	
Not-for-profit	25.0	33.3		24.9	26.2	
Government	7.0	5.4		8.9	7.3	
Score for health status during dialysis§						
Overall health	65.0	58.6	<0.001	65.7	60.7	0.004
Energy	46.3	39.2	<0.001	48.2	43.6	0.006
Emotional well-being	61.2	61.7	0.75	65.1	66.0	0.58
Physical activity	32.8	30.2	0.25	38.3	41.0	0.30

Social activity	55.7	57.6	0.39	58.4	57.7	0.77
Burden of kidney disease on daily life	36.3	34.4	0.30	37.0	35.1	0.32
Coexisting illness (%)¶						
Coronary heart disease	14.3	21.7	0.02	12.6	24.3	0.001
Congestive heart failure	9.7	12.6	0.25	11.9	11.6	0.91
Peripheral vascular disease	6.9	9.2	0.28	4.9	9.7	0.03
Chronic lung disease	3.1	2.0	0.40	2.8	3.7	0.54
Cancer	4.1	3.4	0.67	2.5	2.2	0.87

*Percentages may not sum to 100, because of rounding. ESRD denotes end-stage renal disease.

†Pearson's chi-square test or Student's t-test was used for comparisons of black and white patients with stratification according to sex.

‡Patients with private health insurance may or may not have had Medicare or Medicaid coverage.

§Health status was scored on scales from 0 (poor) to 100 (excellent).

¶Data are based on medical records for 321 black women (83.6 percent of black women), 294 white women (83.1 percent of white women), 286 black men (84.9 percent of black men), and 268 white men (84.5 percent of white men).

Table 1. Demographic and Clinical Characteristics of the Study Cohort.

Preferences and Experiences with Care

Black patients were less likely than white patients to want a kidney transplant, to be very certain about this preference, and to expect that their quality of life would improve with transplantation (Table 2) ($P<0.01$ for each comparison with both sexes combined). Black men were less likely than white men to expect to live longer with a transplant ($P=0.04$), but black and white women had similar expectations about their survival with a transplant ($P=0.72$); when the sexes were combined, the difference between black patients and white patients was of borderline significance ($P=0.07$).

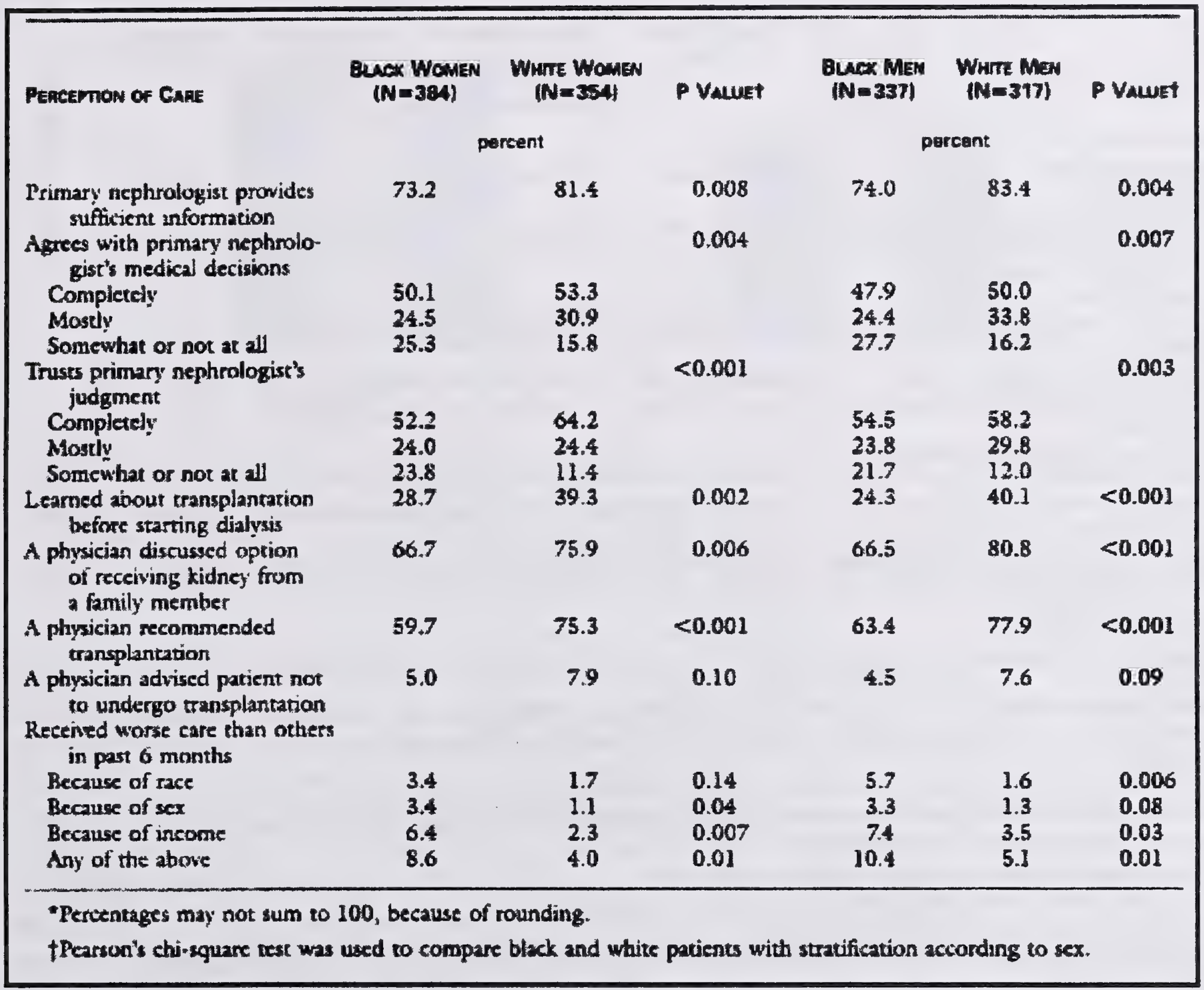
VARIABLE	BLACK WOMEN (N=384)	WHITE WOMEN (N=354)	P VALUE†	BLACK MEN (N=337)	WHITE MEN (N=317)	P VALUE†
	percent			percent		
Want to receive a renal transplant			0.13			0.04
Yes	76.3	79.3		80.7	85.5	
No	9.4	11.1		5.7	6.9	
Not sure	14.3	9.6		13.6	7.6	
"Very certain" about preference for a renal transplant	58.3	65.3	0.05	64.1	75.7	0.001
Expected quality of life with transplantation as compared with dialysis			0.09			0.06
Better	84.1	90.1		85.8	91.8	
About the same	6.8	3.7		6.8	4.1	
Worse	1.6	1.4		3.3	1.0	
Not sure	7.5	4.8		4.1	3.1	
Expected survival with transplantation as compared with dialysis			0.72			0.04
Longer	57.8	61.6		57.0	66.6	
About the same	22.4	20.3		21.7	19.9	
Shorter	3.4	2.5		4.4	3.1	
Not sure	16.4	15.5		16.9	10.4	

*Percentages may not sum to 100, because of rounding.

†Pearson's chi-square test was used to compare black and white patients with stratification according to sex.

Table 2. Patients' Preferences and Expectations with Regard to Transplantation, According to Race and Sex.

Blacks were less likely than whites to report that their primary nephrologist provided all the medical information they desired, that they agreed with this doctor about how to manage their health conditions, and that they trusted this doctor's judgment about their medical care (Table 3). Black patients were less likely to report that they had learned about transplantation before undergoing dialysis or that a physician had discussed the possibility of receiving a kidney from a family member. Black and white women were similarly likely to report that they had a family member who was willing to donate a kidney (53.9 percent and 52.0 percent, respectively; P=0.60), but black men were less likely than white men to report that they had a potential family donor (45.7 percent vs. 53.3 percent, P=0.05).



PERCEPTION OF CARE	BLACK WOMEN (N=384)	WHITE WOMEN (N=354)	P VALUE†	BLACK MEN (N=337)	WHITE MEN (N=317)	P VALUE†
	percent			percent		
Primary nephrologist provides sufficient information	73.2	81.4	0.008	74.0	83.4	0.004
Agrees with primary nephrologist's medical decisions			0.004			0.007
Completely	50.1	53.3		47.9	50.0	
Mostly	24.5	30.9		24.4	33.8	
Somewhat or not at all	25.3	15.8		27.7	16.2	
Trusts primary nephrologist's judgment			<0.001			0.003
Completely	52.2	64.2		54.5	58.2	
Mostly	24.0	24.4		23.8	29.8	
Somewhat or not at all	23.8	11.4		21.7	12.0	
Learned about transplantation before starting dialysis	28.7	39.3	0.002	24.3	40.1	<0.001
A physician discussed option of receiving kidney from a family member	66.7	75.9	0.006	66.5	80.8	<0.001
A physician recommended transplantation	59.7	75.3	<0.001	63.4	77.9	<0.001
A physician advised patient not to undergo transplantation	5.0	7.9	0.10	4.5	7.6	0.09
Received worse care than others in past 6 months						
Because of race	3.4	1.7	0.14	5.7	1.6	0.006
Because of sex	3.4	1.1	0.04	3.3	1.3	0.08
Because of income	6.4	2.3	0.007	7.4	3.5	0.03
Any of the above	8.6	4.0	0.01	10.4	5.1	0.01

*Percentages may not sum to 100, because of rounding.

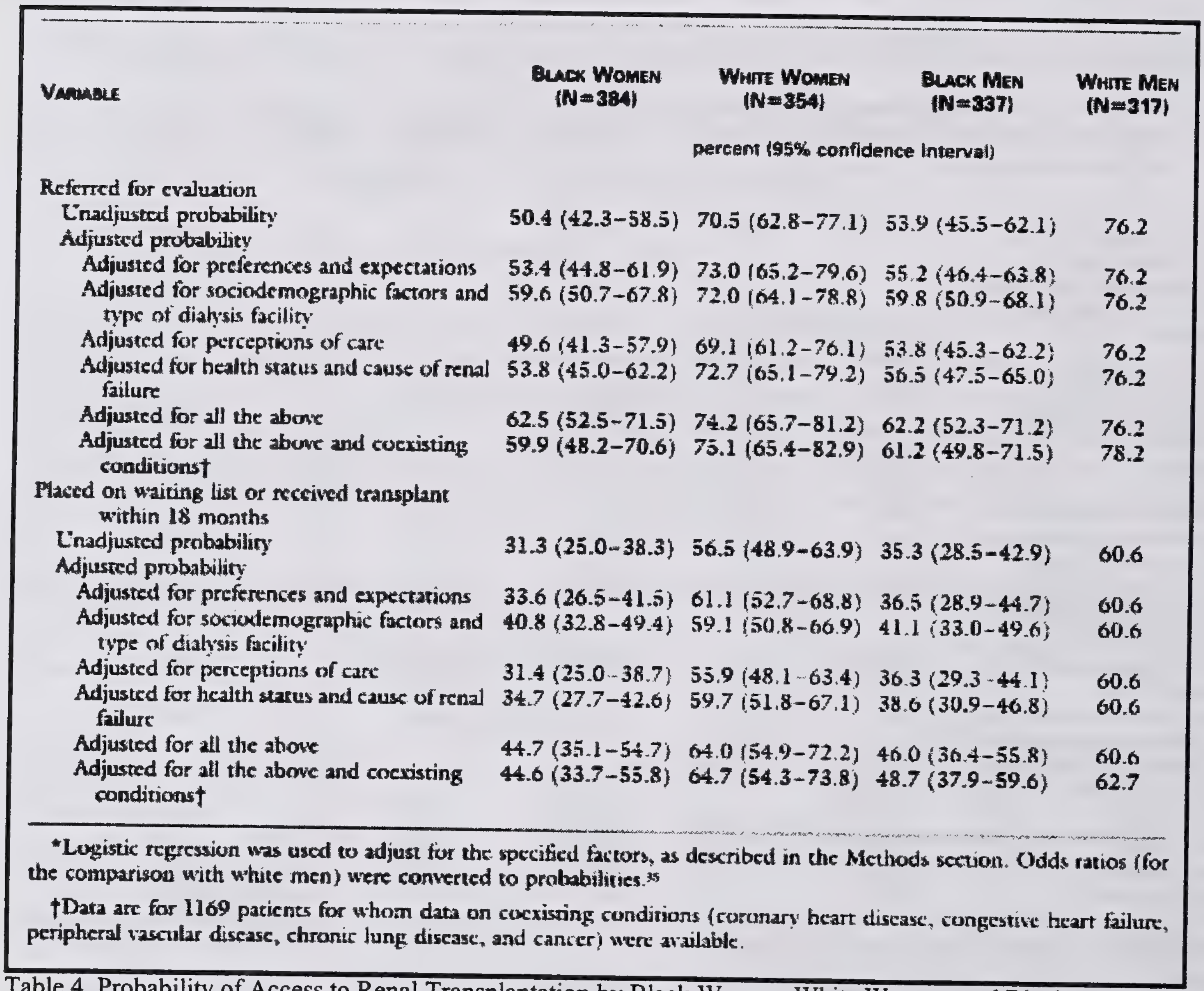
†Pearson's chi-square test was used to compare black and white patients with stratification according to sex.

Table 3. Patients' Perceptions of Medical Care, According to Race and Sex.

Although few patients of either race reported that a physician had advised them not to undergo transplantation, black patients were less likely to report that a physician had recommended it. Black patients were more likely than white patients to report that they had received worse medical care than other patients during the previous six months because of their race, income, or sex, but the absolute differences according to race were relatively small.

Access to Transplantation

In contrast to the relatively small differences in preferences and expectations about transplantation, black patients were much less likely than white patients to have been referred to a transplantation center for evaluation; they were also much less likely to have been placed on a waiting list or to have received a transplant within 18 months after the initiation of dialysis (Table 4). These differences were similar in magnitude and were significant (P<0.04) in three of the four regions (data not shown); the exception was southern California, where black and white women had similar rates of referral (57.0 percent and 60.0 percent, respectively; P=0.70). Among the 1169 patients whose medical records we obtained, blacks were less likely to have been referred, according to these records (55.5 percent of black women vs. 75.2 percent of white women, and 60.4 percent of black men vs. 82.3 percent of white men; P<0.001 for each comparison).



VARIABLE	BLACK WOMEN (N=384)	WHITE WOMEN (N=354)	BLACK MEN (N=337)	WHITE MEN (N=317)
	percent (95% confidence interval)			
Referred for evaluation				
Unadjusted probability	50.4 (42.3–58.5)	70.5 (62.8–77.1)	53.9 (45.5–62.1)	76.2
Adjusted probability				
Adjusted for preferences and expectations	53.4 (44.8–61.9)	73.0 (65.2–79.6)	55.2 (46.4–63.8)	76.2
Adjusted for sociodemographic factors and type of dialysis facility	59.6 (50.7–67.8)	72.0 (64.1–78.8)	59.8 (50.9–68.1)	76.2
Adjusted for perceptions of care	49.6 (41.3–57.9)	69.1 (61.2–76.1)	53.8 (45.3–62.2)	76.2
Adjusted for health status and cause of renal failure	53.8 (45.0–62.2)	72.7 (65.1–79.2)	56.5 (47.5–65.0)	76.2
Adjusted for all the above	62.5 (52.5–71.5)	74.2 (65.7–81.2)	62.2 (52.3–71.2)	76.2
Adjusted for all the above and coexisting conditions†	59.9 (48.2–70.6)	75.1 (65.4–82.9)	61.2 (49.8–71.5)	78.2
Placed on waiting list or received transplant within 18 months				
Unadjusted probability	31.3 (25.0–38.3)	56.5 (48.9–63.9)	35.3 (28.5–42.9)	60.6
Adjusted probability				
Adjusted for preferences and expectations	33.6 (26.5–41.5)	61.1 (52.7–68.8)	36.5 (28.9–44.7)	60.6
Adjusted for sociodemographic factors and type of dialysis facility	40.8 (32.8–49.4)	59.1 (50.8–66.9)	41.1 (33.0–49.6)	60.6
Adjusted for perceptions of care	31.4 (25.0–38.7)	55.9 (48.1–63.4)	36.3 (29.3–44.1)	60.6
Adjusted for health status and cause of renal failure	34.7 (27.7–42.6)	59.7 (51.8–67.1)	38.6 (30.9–46.8)	60.6
Adjusted for all the above	44.7 (35.1–54.7)	64.0 (54.9–72.2)	46.0 (36.4–55.8)	60.6
Adjusted for all the above and coexisting conditions†	44.6 (33.7–55.8)	64.7 (54.3–73.8)	48.7 (37.9–59.6)	62.7

*Logistic regression was used to adjust for the specified factors, as described in the Methods section. Odds ratios (for the comparison with white men) were converted to probabilities.[35]

†Data are for 1169 patients for whom data on coexisting conditions (coronary heart disease, congestive heart failure, peripheral vascular disease, chronic lung disease, and cancer) were available.

Table 4. Probability of Access to Renal Transplantation by Black Women, White Women, and Black Men, as Compared with White Men.

Among patients who wanted a transplant, blacks remained significantly less likely than whites to have been referred for evaluation and significantly less likely to have been placed on a waiting list or to have received a transplant within 18 months after the start of dialysis therapy (Figure 1). Even among the patients who said they were very certain that they wanted a transplant, blacks were substantially less likely than whites to have been referred for evaluation (62.8 percent of black women vs. 83.6 percent of white women, and 62.0 percent of black men vs. 83.2 percent of white men; P<0.001 for each comparison) and were substantially less likely to have been placed on a waiting list or to have received a transplant within 18 months after the start of dialysis therapy (44.2 percent vs. 71.4 percent and 45.4 percent vs. 70.8 percent, respectively; P<0.001 for each comparison). After the exclusion of the 56 patients who received transplants from living donors and were not placed on a waiting list, black women and men were less likely than white women and men to have been placed on a waiting list within 18 months after the initiation of dialysis therapy (30.2 percent vs. 52.7 percent and 34.1 percent vs. 57.2 percent, respectively; P<0.001).

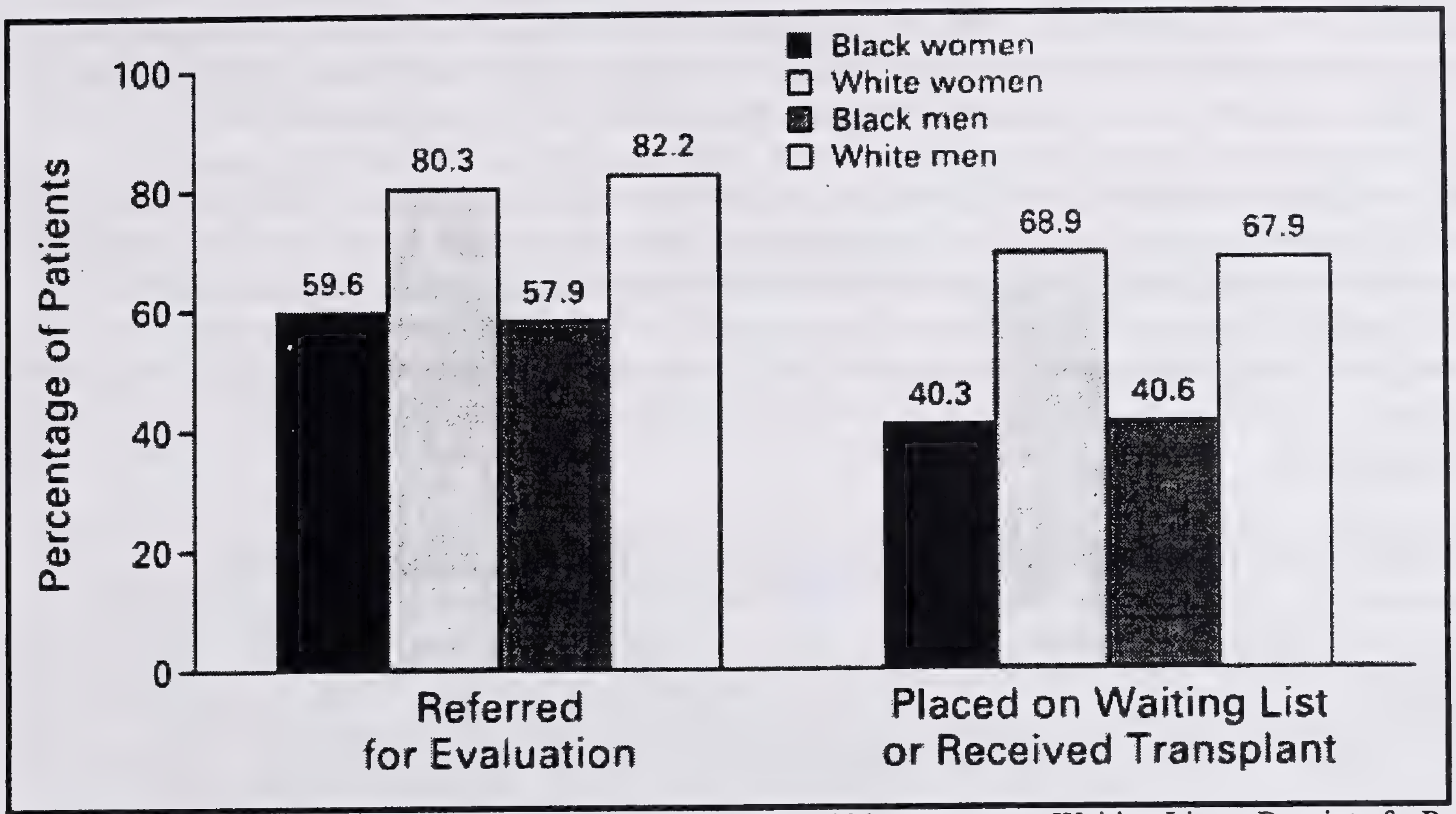


Figure 1. Referral for Evaluation at a Transplantation Center and Placement on a Waiting List or Receipt of a Renal Transplant within 18 Months after the Start of Dialysis among Patients Who Wanted a Transplant, According to Race and Sex. The data are based on a total of 293 black women, 280 white women, 271 black men, and 271 white men. Racial differences were statistically significant among the women and among the men (P<0.001 for each comparison).

With adjustment for patients' preferences with respect to transplantation and numerous other potential confounders, black women and men were still significantly less likely than white men to have been referred for evaluation and placed on a waiting list for a transplant or to have received a transplant within 18 months after the start of dialysis therapy (Table 4). Racial differences in access remained significant after we also controlled for coexisting illnesses among patients whose medical records were available. These potential confounders together explained less than half the absolute unadjusted difference in access to transplantation according to race. Sex was not a significant predictor of access to transplantation among black or white patients. With the exclusion of patients who received transplants from living donors and were not placed on a waiting list, black women and men were still significantly less likely than white men to be placed on a waiting list, after adjustment for all other variables in the full logistic-regression model (data not shown).

After adjustment for all the variables we have described, patients undergoing dialysis at the for-profit facilities in our study did not differ significantly from patients undergoing dialysis at not-for-profit facilities with respect to the proportions of patients who had been referred for evaluation at a transplantation center (odds ratio, 0.99; 95 percent confidence interval, 0.71 to 1.38; P=0.95). Whereas Garg et al., as reported elsewhere in this issue of the Journal, [34] found a significantly lower likelihood of having been placed on a waiting list among patients treated at for-profit dialysis centers, we did not find such an association within 18 months after the start of dialysis therapy, after excluding the patients who received transplants from living donors without having been placed on a waiting list (adjusted odds ratio, 0.90; 95 percent confidence interval, 0.65 to 1.26; P=0.55).

Significant predictors of referral in the full multivariable model included wanting a transplant and being very certain about this preference, being younger, being a college graduate, having private insurance, reporting better physical functioning, reporting a greater burden of kidney disease on daily life, and residing in Michigan. Significant predictors of placement on a waiting list or receipt of a transplant within 18 months after the start of dialysis therapy included wanting a transplant and being very certain about this preference, expecting to live longer with a transplant, being younger, being a college graduate, having private insurance, being employed, owning an automobile, reporting less energy and better physical functioning while on dialysis, and reporting greater agreement with nephrologists' medical decisions. Patients in southern California were less likely than other patients to be on a waiting list for a transplant or to have received one. In the secondary multivariable analysis of patients whose medical records were available, those with a history of congestive heart failure, peripheral vascular disease, chronic lung disease, or cancer were significantly less likely than others to be on a waiting list for a transplant or to have received one.

Discussion

We assessed whether patients' preferences explained racial differences in access to renal transplantation. Our findings that blacks were much less likely than whites to have been referred for evaluation at a transplantation center and were much less likely to have been placed on a waiting list or to have received a transplant were consistent with the results of previous studies. [9-11] In our study, blacks were less likely than whites to want a transplant or to be very certain about this preference, but these views explained only a small part of the racial differences in rates of referral and of placement on a waiting list or transplantation. Racial differences in access to transplantation remained significant after adjustment for sociodemographic factors, health status, perceptions of care, and coexisting illnesses.

If racial differences in the rates of procedures reflected the preferences of well-informed patients, then such differences might represent acceptable variations in care. Among the patients in our study who desired transplantation, however, black patients were less likely than white patients to have been evaluated and placed on a waiting list or given a transplant. Although few patients reported recent discrimination on the basis of their race, income, or sex, we believe blacks may be more likely than whites to encounter problems in communicating with their physicians and may have less trust in the health care system, [36,37] as suggested by our data and the preliminary results of one qualitative study. [38]

Our findings build on other studies that have reported indirect measures of patients' preferences with respect to major procedures according to race. In the Coronary Artery Surgery Study, black laborers were less likely than white laborers to undergo recommended surgery, possibly reflecting their preferences or other factors such as financial barriers. [23] In smaller studies involving hypothetical recommendations to undergo invasive cardiovascular or cerebrovascular procedures, black patients tended to be less willing than white patients to accept these recommendations [24,25] or the risk associated with surgery. [26] In a survey of patients with end-stage renal disease, blacks had more reservations than whites about transplantation, but the patients' desire to undergo transplantation was not assessed directly. [27] Our data on patients' preferences and experiences with regard to a major procedure complement a recent study involving simulated patients in which physicians were found to be less likely to recommend coronary angiography for black women than for other patients, despite similar clinical characteristics. [39]

The strengths of our study include the size and geographic diversity of our sample, the high response rate, and direct reports of patients' preferences and experiences with regard to medical care. We also confirmed patients' reports of whether they were referred for transplantation by obtaining medical records for more than four fifths of the respondents. However, some patients may not have accurately recalled other information that they reported. Another limitation of our study is that we did not assess barriers to transplantation after patients were referred for evaluation - for example, by determining their ability and willingness to travel to transplantation centers or to complete diagnostic testing. [11] Racial differences in patients' preferences should also be evaluated for other major procedures - such as coronary-artery bypass surgery and carotid endarterectomy - that are often performed in patients older than those we studied.

Racial differences in access to renal transplantation are pervasive, [9] but they are not immutable. [40] Approaches to improving black patients' access include providing more systematic education about transplantation, offering greater encouragement to undergo evaluation for transplantation and to consider potential living donors, and monitoring and informing physicians and medical groups about racial differences in referral rates among their own patients. By making renal transplantation available to all clinically appropriate candidates who desire it, such efforts would foster greater effectiveness and racial equity in the use of this valuable procedure.

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Racial Disparity in Rates of Surgery for Lung Cancer

[Editorials]

King, Talmadge E. Jr.; Brunetta, Paul.

(T.E.K., P.B.) University of California, San Francisco; San Francisco, CA 94143

Outline

- REFERENCES

Lung cancer is the leading cause of death from cancer in the United States, accounting for more deaths per year than cancers of the breast, colon, prostate, and cervix combined. Blacks have a higher incidence of and death rate from lung cancer than whites. The incidence rates differ significantly among men (122 per 100,000 population for blacks, as compared with 78 per 100,000 for whites), whereas the rates among black women and white women are similar. Overall, the five-year survival rate for lung cancer is 14 percent among whites and 11 percent among blacks.

Some of the difference in the incidence of lung cancer can be explained. Cigarette smoking, the predominant risk factor, accounts for 80 to 90 percent of all cases. The risk is related to the number of cigarettes smoked, the age at which smoking began, and the duration of smoking. [1] Black men have higher rates of cigarette smoking than white men (34 percent vs. 28 percent), whereas black women have lower rates than white women (22 percent vs. 25 percent). Women may be at greater risk for lung cancer than men at a given level of smoking. Tobacco companies have targeted blacks, especially teenagers, with aggressive advertising and promotion. During this decade, the prevalence of smoking increased by 80 percent among black high-school students (from 13 percent to 23 percent), with the most dramatic increase occurring among young black men - from 14 percent to 28 percent. Unfortunately, exposure of blacks to other respiratory carcinogens (particularly occupational exposure, air pollution, and dietary factors) has not been adequately studied.

The reasons for the higher death rate among blacks with lung cancer are more complex. [2] Most of the blame has been placed on health-related behavior, socioeconomic status, or lack of access to medical care. However, studies suggest that these factors account for only a portion of the inequalities in morbidity and mortality. [2] Therefore, other explanations should be sought. Blacks smoke fewer cigarettes than whites, but they tend to smoke mentholated cigarettes or ones with higher levels of nicotine and tar. Also, black smokers have higher blood levels of cotinine (the main metabolite of nicotine), [3,4] and the carcinogenic or mutagenic agents in tobacco smoke may be metabolized and excreted at different rates in blacks as compared with whites. [5,6] These differences may help explain the greater risks of both addiction to nicotine and the adverse health consequences of smoking - cancer, heart disease, and stroke - among blacks.

In this issue of the Journal, Bach et al. [7] present results from an observational study in which data from two large national data bases - that of the Surveillance, Epidemiology, and End Results (SEER) program and Medicare hospitalization records - were used to assess the rates of resection and survival among elderly patients (greater/equal 65 years of age) with early-stage, non-small-cell lung cancer (i.e., cancer confined to the lung or regional lymph nodes without mediastinal or other metastatic spread [stage I or stage II]). There is agreement that surgical resection saves lives in patients with early-stage, non-small-cell lung cancer. After accounting for the confounding effects of sex, coexisting illness, socioeconomic status, insurance coverage, and availability of care, the study showed that black patients, once lung cancer had been diagnosed and staged, were 12.7 percent less likely than white patients to undergo surgical resection. Blacks also had a lower five-year survival rate than whites. The authors concluded that if blacks were to undergo surgery at the same rate as whites, the survival rate among blacks would be substantially improved and almost equal to that among whites.

What are the implications of this study? The findings of this study and others [8] suggest that there is a difference in how physicians manage cancer that is based on a patient's race, regardless of other attributes, and that the consequence of these lapses in care is reduced survival among blacks. Evidence that bias on the part of physicians (either overt prejudice or subconscious perceptions) influences access to optimal cancer care is disheartening, because we all believe that if our loved ones get cancer, they will receive the best care available. We do not presume to know whether bias is truly at work in this setting, but we must strive to remove any barrier preventing blacks from using the health care system for the prevention, diagnosis, and treatment of cancer.

Many physicians either do not know or fail to adhere to established standards for the diagnosis and staging of lung cancer. [1] An alarming 35.4 percent of the patients in the study by Bach et al. were excluded from the analysis because of inadequate documentation of the tumor stage - a crucial step in the formulation of treatment recommendations. [7] This finding should be the focus of future investigation, since it underscores the effect of poor pretreatment evaluations.

Racial differences between physicians and patients are often barriers to optimal patient-physician communication and partnership. [9] Black patients are more likely than whites to feel excluded from decisions affecting their health, and this feeling may be an important factor contributing to miscommunication, increased suspicion of the health care system, and concern about mistreatment. Failure to address the very real issues of cross-cultural communication and variations in beliefs about health threatens patients' satisfaction and clinical outcomes. Recent initiatives at medical schools to teach "professionalism" and "cultural competence" should be lauded and expanded. [10,11]

Both black patients and white patients appear more likely to feel involved with their own care when their doctors are of the same race. [9] However, black patients are far less likely to have a black physician as part of their care team. Although blacks make up 12 percent of the U.S. population, only 4 percent of physicians are black. Despite their low numbers, black physicians have a unique and important role in the care provided to poor or minority communities. [12] Consequently, the dismantling of programs designed to encourage members of minority groups to enter the health profession threatens the health of blacks and other minority groups. [12]

The lack of preventive services and appropriate cancer-screening tests is a known weakness of the American health care system. Despite the fact that tobacco use is the most costly and deadly cause of preventable disease, graduates of U.S. medical schools are not adequately trained to treat nicotine dependence. [13] For lung cancer, as compared with other common cancers, there is no regular screening test to enhance early detection and reduce mortality. [1] In a recent study of spiral computed tomographic scanning as a screening procedure, early lung cancer was detected in 2.7 percent of 1000 subjects with a history of at least 10 pack-years of smoking, which compares favorably with the rate of detection of prostate cancer with screening for prostate-specific antigen. [14] This exciting finding may spur a resurgence of early-screening initiatives.

More effective screening will make surgical resection for early-stage lung cancer more important, and any racial disparity in resection rates, if not corrected, will be even more glaring. Many blacks do not undergo preventive screening for cancer, because their physicians do not recommend the tests. [2] Should effective screening for lung cancer become available, we will need large-scale public health initiatives to make black patients, and their physicians, aware of its importance. Finally, since patients without medical insurance and those with low incomes undergo screening and needed surgery less often than other patients, we need to ensure universal access to appropriate care.

Most of the knowledge about the best treatment for patients with lung cancer has and will come from large, properly conducted clinical trials. Unfortunately, many blacks are reluctant to enroll in clinical trials - the aftermath of several shameful episodes in the history of U.S. research. President Bill Clinton's formal apology to the remaining survivors of the Tuskegee Study of Untreated Syphilis was more than symbolic - it was a start toward the rebuilding of trust. [15] Physicians making treatment recommendations to black patients must be sensitive to this issue. Also, agencies that fund research on cancer should devote more resources to remedying the disproportionate effect of cancer on minority groups and the medically underserved. [8] They should also ensure adequate representation of racial and ethnic minority groups in cancer studies, increase the number of persons from minority groups who perform cancer research and participate in the setting of research priorities, and increase efforts to attract investigators from minority groups to work on cancer issues and serve on advisory panels. [8] It is important to note that research on lung cancer remains grossly underfunded (at a level estimated to be $800 per death, as compared with $30,000 per death from AIDS and $10,000 per death from breast cancer).

Preventing lung cancer is easier than curing it, and survival is better if the cancer is diagnosed early in an asymptomatic patient and treated with surgical resection. If the poor statistics on survival for the leading cause of cancer deaths in the United States are partially due to racial discrimination that results in an inadequate emphasis on prevention or insufficiently aggressive care for blacks, then the medical establishment begins to share a portion of the tobacco industry's culpability for the dismal outcome of patients with this disease. Like a time bomb, lung cancer should be rapidly evaluated and defused. Every educational, social, political, and legal effort should be made to ensure that all patients with lung cancer receive high-quality care - appropriate services delivered in a technically competent manner, with good communication, shared decision making, and cultural sensitivity. [2]

Talmadge E. King, Jr., M.D.

Paul Brunetta, M.D.

University of California, San Francisco; San Francisco, CA 94143

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Racial Injustice in Health Care

[Editorials]

Freeman, Harold P.; Payne, Richard.

North General Hospital; New York, NY 10035 (Freeman)
Memorial Sloan-Kettering Cancer Center; New York, NY 10021 (Payne)

Outline

- REFERENCES

A growing body of compelling and disturbing evidence points to inferior medical care for black Americans, even if they are on an equal economic footing with whites. Differences in access to treatment and the quality of care are at least part of the reason why the rates of death from some diseases are higher among blacks than among whites.

In this issue of the Journal, Morrison et al. show that black and Hispanic patients with severe pain are less likely than white patients to be able to obtain commonly prescribed pain medicines, because pharmacies in predominantly nonwhite communities do not carry adequate stocks of opioids. [1] Concern about illicit use of drugs and fear of theft were among the reasons pharmacists gave for not stocking opioids. However, neighborhood discrepancies in supplies of pain medication persisted after adjustment for crime rates and drug-related arrests in local police precincts. The authors also reported that 54 percent of the surveyed pharmacists claimed that they did not stock opioid analgesics because there was little demand for these medications. This explanation, if validated, indicates that physicians in minority neighborhoods share some of the blame for the undertreatment of pain in their communities.

Black Americans have a higher overall incidence of cancer and a higher rate of death from cancer than any other racial or ethnic group. [2] The findings of Morrison et al. lead us to believe that in addition to these burdens, blacks are also inadequately treated for pain from cancer.

The following true case illustrates the problem a black person actually faces in obtaining pain medication from a local pharmacy. A 72-year-old black woman with metastatic breast cancer who lived in Harlem with her daughter was receiving palliative care at home under the supervision of physicians from a large hospital in New York City. Because of severe bone pain that was unrelieved by previously prescribed analgesics, she was visited by a physician from the hospital and given a prescription for a morphine-based preparation. Her daughter went to four different neighborhood pharmacies in search of the medicine; at all four, she was informed that they did not carry morphine-containing medications. Finally, the daughter called the prescribing physician, who arranged for a home care team to deliver the medicine to the patient's home. Ten hours after the physician's house call, the patient at last received the prescribed pain medication.

The problem goes beyond cancer pain. Other studies have shown variations in doses of analgesics administered in emergency departments. Two studies showed that Hispanics and blacks were substantially undertreated for pain from fractures of long bones. [3,4] Another study found that postoperative pain was inadequately managed if the patient was not white. [5]

Apart from inadequate treatment for pain, there is convincing evidence that blacks are less likely than whites to receive curative surgery for early-stage lung, colon, or breast cancer. [6-8] Particularly troubling is the recent finding that the lower survival rate among black as compared with white patients with early-stage lung cancer is due largely to a lower rate of potentially curative surgery among blacks. The two groups did not differ significantly with respect to socioeconomic status, insurance coverage, or access to care. Furthermore, blacks with chronic renal failure are less likely to be referred for transplantation and are less likely to undergo transplantation than are whites. Ayanian et al. [9] reported that the rate of referral for evaluation at a transplantation center was 50.4 percent for black women, as compared with 70.5 percent for white women, and 53.9 percent for black men, as compared with 76.2 percent for white men. These racial differences remained significant after adjustments for patients' preferences, sociodemographic characteristics, the cause of renal failure, and the presence or absence of coexisting illness. Blacks are also not as likely as whites to undergo a thorough diagnostic evaluation for symptoms that suggest the presence of life-threatening coronary artery disease. [10]

We believe the common thread in these findings is a subtle form of racial bias on the part of medical care providers. The level and extent of this problem are unknown, but it is real and potentially harmful, even though predominantly unintentional. Americans, we believe, perceive, value, and behave toward one another through a lens of race. This lens can create false assumptions that result in unintended but serious harm to members of minority groups - especially those who are powerless and vulnerable.

How can we remedy these unacceptable facts? As a starting point, we recommend nationally and locally supported campaigns to create a high level of awareness of these issues among medical trainees and professionals. It is also important to establish and monitor standards of medical care, with special attention paid to the quality of pain control and palliative care.

Everything we know about population genetics, the human genome, and physical anthropology makes it clear that racial classification has no scientific basis. Race is a social construct determined primarily by how one group perceives, values, and behaves toward another group. [11] The power of science can be used to eliminate false perceptions of the meaning of race and could prove pivotal in moving our society toward racial justice and reconciliation. Physicians and scientists must be leaders in promoting this evolution in understanding.

Physicians, as well as pharmacists, police officers, and others, must learn to see people not through the lens of race but instead as the individual persons they are. Appropriate judgments and actions in medicine and in society at large will follow.

Harold P. Freeman, M.D.

North General Hospital; New York, NY 10035

Richard Payne, M.D.

Memorial Sloan-Kettering Cancer Center; New York, NY 10021

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level of antigen-presenting cells such as dendritic cells[10] and stimulates osteoclast-mediated bone resorption directly or indirectly by the receptor activator of nuclear factor-κB and its ligand.[11] Histologic studies of synovial-biopsy specimens from patients with spondyloarthropathies who were being treated with anti–TNF-α agents have shown reductions in the thickness of the synovial lining, vascularity, and cellular infiltration with neutrophils, macrophages, and T and B cells.[7,8] In contrast, the use of these agents in patients with rheumatoid arthritis is associated with decreased numbers of macrophages; alterations in lymphocyte infiltration are less striking.

In the study by Gorman et al., the marked changes that resulted from etanercept therapy were mostly subjective. They included decreases in stiffness and pain and improvement in overall function, along with objective findings such as an increase in chest expansion and a decrease in the erythrocyte sedimentation rate. As one would expect, there was little peripheral-joint involvement in the cohort, and one might wonder why it was deemed necessary to examine 66 joints without specifically mentioning sacroiliac joints. Because peripheral-joint involvement was minimal, the difference between the etanercept and placebo groups in the change from base-line scores for joint tenderness was not significant. There was no major change in scores for fatigue, whereas therapy with anti–TNF-α agents reduces fatigue in patients with rheumatoid arthritis[10]; these conflicting findings provide further evidence of differences between the disorders. As for side effects, there has to be concern about the possibility of neurologic complications in the light of reports of demyelinating disease in patients with other disorders who have been treated with etanercept.[12] Regrettably, only a few biologic abnormalities were assessed in the current study (the erythrocyte sedimentation rate and C-reactive protein), and the most sophisticated imaging methods were not used. In a smaller study of patients with spondyloarthropathy,[13] magnetic resonance imaging was very useful for assessing the response of lesions to treatment with etanercept. Such techniques may prove useful in assessing specific features of ankylosing spondylitis, such as periosteal reactions and ectopic ossification of ligaments. Improved biologic monitoring during the course of treatment with the same agent in patients with different immunoinflammatory diseases would lead to a better understanding of the pathogenesis of these disorders and would help identify the best markers of a treatment response. With all the new scientific tools available, a combined effort on the part of academic researchers and pharmaceutical companies is needed to identify the patients who are most likely to benefit from TNF-α inhibition, not only because of the cost of this treatment but also because of its possible long-term side effects.

JEAN-MICHEL DAYER, M.D.
Geneva University School of Medicine
1211 Geneva 14, Switzerland

STEPHEN M. KRANE, M.D.
Massachusetts General Hospital–East
Charlestown, MA 02129

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Racial Disparities in Clinical Trials

THE rational use of a new drug or treatment should be based on the results of controlled clinical trials that are well designed, avoid bias, and include subjects representing the full range of patients who are likely to receive the treatment once it is marketed. In addition to age, sex, diet, underlying disease, and the concomitant use of other medications, race and genetic factors may play pivotal parts in the variability of subjects' responses to a medication.[1] Regrettably, minority groups are underrepresented in most clinical trials. Often, there are insufficient data to assess the effectiveness or safety of new drugs in members of minority groups, especially blacks. Concern about this issue led the National Institutes of Health[2] and the Food and Drug Administration[3] to establish guidelines encouraging the inclusion of more women and minority groups in clinical trials. However, it is uncertain whether these guidelines are being implemented and whether the participation of minority groups in clinical trials has increased.

In this issue of the *Journal,* Gifford and colleagues[4] report that an impressive 14 percent of adults receiving care for human immunodeficiency virus (HIV) infection in the United States participated in a clinical study between 1996 and 1998, and 24 percent received an experimental medication during that period. An additional 8 percent tried unsuccessfully to get experimental HIV treatments. Gifford et al. analyzed data from the HIV Cost and Services Utilization Study cohort — a reference population of 2864 persons who are representative of the 231,400 adults with known HIV infection who made at least one visit for regular health care (other than to an emergency department or a military or prison facility) in the 48 contiguous United States in early 1996. Factors associated with participation in a clinical trial of HIV treatment included non-Hispanic white race, male sex, a history of male homosexual contact, education beyond the high-school level, an annual income of more than $25,000, private fee-for-service health insurance, and residence within one mile of a center participating in such a trial. Non-Hispanic blacks and Hispanic persons were less likely to participate in trials than non-Hispanic whites. Of blacks who were enrolled in clinical trials at the start of the study, only 25 percent were enrolled in trials at follow-up, as compared with 53 percent of whites.

The report by Gifford et al. has important implications for the care of people with HIV infection and the representation of minority groups in clinical trials. Much of the improvement in outcomes for patients with HIV infection resulted from the widespread use, after 1996, of highly active antiretroviral therapy. Remarkably, by 1998, 90 percent of HIV-infected patients with private insurance and 79 percent of patients without health insurance had received such therapy.[5] Despite these encouraging data, Gifford and colleagues show that black race and Hispanic or "other" ethnic background negatively influenced access to clinical trials.[4] This disparity persisted in their study even for blacks who tried to get experimental medications.

Moreover, providers who were experienced in the treatment of HIV infection (and were therefore most likely to be involved in or to know about clinical trials) cared for most of the patients in this cohort. Thus, one inference might be that either overt prejudices or subconscious perceptions on the part of these physicians influenced access to HIV-related clinical trials. Because these data were generated in a nationally representative cohort of HIV-infected persons receiving regular medical care, the problem may be pervasive.

Why are minority groups underrepresented in clinical trials of treatments for HIV infection? There are barriers at the levels of the patient, the physician, the institution, and the community.[6-8] Although a complete discussion of these barriers is beyond the scope of this editorial, several key points can be made. Beliefs, behavior, attitudes, perceptions, and expectations influence both patients and physicians. Moreover, these factors may affect the patient–physician relationship in ways that neither party consciously perceives. Physicians need to recognize and accept the fact that despite their desire to view each patient objectively and to base decision making on biomedical information about that patient, it is often impossible to meet this goal.[9] Limited data suggest that health care providers, like the rest of society, harbor prejudicial attitudes (biases or stereotyping) toward minority groups — particularly blacks. Furthermore, these attitudes may influence a provider's decisions about treatment.[9,10] Patients often respond to such attitudes with mistrust of the physician and reluctance to comply with treatment.[9] This dynamic is particularly important in the informed-consent process (designed to inform patients of the risks and benefits associated with participation in a clinical trial and to facilitate self-determination), during which a lack of trust often leads to the patient's refusal to enter a clinical trial.[11] Many blacks view signing the informed-consent document as relinquishing their autonomy and providing legal protection for the physician or the institution.[11]

Breaches of trust on the part of the patient or the physician appear to be a major factor contributing to disparities in the care provided to members of racial and ethnic minority groups.[12] Health care workers who exhibit humane qualities (e.g., compassion, empathy, and honesty) and communicate in a respectful and culturally appropriate manner foster trust. Trust increases the patient's involvement in care, adherence to recommended treatment, and willingness to participate in research.

The failure of drugs due to viral resistance is a common and serious problem in antiretroviral therapy. The consistency of adherence to highly active antiretroviral therapy predicts the biologic outcomes for HIV-infected persons in clinical trials.[13] Pharmaceutical companies, as part of their efforts to obtain licensing approval, perform most trials of anti-HIV drugs. Consequently, researchers purposely avoid recruiting marginalized populations (such as members of minority groups, substance abusers, or homeless persons) to clinical trials because they believe that poor compliance is common in these groups. Many obstacles to participation by such patients (e.g., homelessness, lack of transportation, limited income, lack of child care, and active drug use) are probably surmountable and, more important, in many studies have not predicted poor compliance.[14] Many other factors are also related to adherence, including fluency in English, the level of functional health literacy (a measure of a patient's ability to read and comprehend written information and to perform numerical tasks related to health care),[15] the complexity of the medication regimen, and the efficacy of the regimen. In clinical practice, physicians have to assess each patient's understanding of the prescribed regimen or tailor the regimen to fit the lifestyle of the patient.[14] However, most clinical trials are not designed to deal with these issues, so the population involved in studies rarely mirrors the full spectrum of patients who are likely to receive the treatment. As a result, many trials of antiretroviral drugs do not provide information on how to use the medications in routine clinical practice.

Finally, investigators have a narrow view of the sort of person who makes a good participant in an HIV-related clinical trial: a white, college-educated, employed, housed, homosexual man. As a result, they have a more difficult time recruiting patients for such trials. In part, recruitment is difficult because many drugs are already available, combination therapy works, and the health of HIV-infected patients is improving. Many patients are reluctant to enroll in new trials, and their physicians, many of whom have a "let's wait and see" attitude, do little to encourage them. But the battle is far from over. The scientific and health care communities must continue aggressive efforts to educate patients with HIV infection about clinical trials and to motivate and encourage them to participate in such trials. In order to provide generalizable results, trials must involve men and women, both homosexual and heterosexual, of all racial and ethnic groups, irrespective of their financial circumstances.

TALMADGE E. KING, JR., M.D.
San Francisco General Hospital
San Francisco, CA 94110

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IRB REFORM

WE have come a long way since the 1960s, when ethical questions about research involving human subjects brought the issue to national attention. Nonetheless, the current system for safeguarding people who volunteer for clinical trials is under stress because of the unprecedented growth in clinical research.[1-3] Since 1995, federal funding for research has more than doubled. From 1997 to 2000, the estimated number of participants in federally funded research increased from 7 million to almost 12 million[4] (and Seto B: personal communication). Privately sponsored clinical research has grown at a similar pace.[5] To paraphrase Snyderman and Holmes, as our ability to discover expands, we must be ready for the increasingly dominant role of clinical research in medical practice.[6]

Two articles in this issue of the *Journal* examine current efforts to improve the system for reviewing research protocols. Christian et al. describe a central review process for multi-institutional studies that allows institutional review boards (IRBs) to focus on

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Quality and Equity in Dialysis and Renal Transplantation

[Editorials]

Levinsky, Norman G.

Boston University Medical Center; Boston, MA 02118

Outline

- REFERENCES

The Medicare End Stage Renal Disease (ESRD) Program began in 1973. Over the past 26 years, it has illustrated both the benefits of modern, high-technology medicine and the problems associated with it. Life of good quality has been extended for hundreds of thousands of people. However, the cost of the program has increased far beyond original estimates. In 1997, Medicare spent approximately $11.76 billion on the ESRD program, and total spending by all insurers was estimated to be about $15.64 billion. [1] The increase in cost came about mostly because long-term dialysis, originally intended for relatively young patients without systemic illnesses, has increasingly been used to treat older persons and those with coexisting illnesses, such as diabetes.

Medicare formulas for reimbursing long-term treatment with dialysis have been complex; the average payment per treatment was about $138 in 1973 and is currently about $126, of which Medicare reimburses 80 percent. In constant dollars, the rate of reimbursement by Medicare has decreased by about two thirds since 1973. In the earliest years of the Medicare ESRD program, the decreases could be absorbed without eroding the quality of care, because the cost of providing dialysis was reduced by technical innovations and economies of scale. Since the 1980s, there has been mounting concern - supported by some suggestive but not conclusive, evidence - that the quality of care has been eroded by the progressive reduction in inflation-adjusted payments. [2]

At present, two thirds of U.S. patients with ESRD undergo dialysis in for-profit facilities. Some analysts of the American health care system have been uneasy about the involvement of profit-making organizations in medical care. One concern is that for-profit facilities may be more likely than not-for-profit facilities to respond to financial pressures by taking steps that compromise the quality of care. In this issue of the Journal, Garg et al. [3] report on the quality of care in for-profit and not-for-profit dialysis facilities. Using data from large national data bases, they found that mortality was 20 percent higher among patients treated in for-profit rather than not-for-profit facilities. They also report that the likelihood that a patient would be put on the waiting list for a kidney transplant (thereby potentially reducing revenue for a dialysis facility) was 26 percent lower in for-profit facilities. Garg and associates were able to adjust statistically for many demographic, social, and clinical characteristics of the patients and for certain relevant features of the facilities. Although such adjustments for confounding factors cannot entirely rule out possible differences in unmeasured characteristics, the study provides important data about the influence of commercial ownership of dialysis facilities on the quality of care.

The literature on the effect of ownership of dialysis facilities on the quality of care they provide and on the outcomes of long-term dialysis is scanty. One study found that patients who underwent dialysis in investor-owned facilities were less likely to receive kidney transplants than those treated in not-for-profit facilities. [4] An article and two recent abstracts report an unfavorable influence of for-profit ownership of dialysis facilities on the quality of care, as judged by the number of hours patients underwent dialysis [5-7] or by their blood pressure, hematocrit, and serum albumin levels. [7] For-profit facilities administered smaller doses of erythropoietin than did not-for-profit facilities when the reimbursement policy made this practice more profitable. [8]

Earlier studies indicated that in response to decreasing Medicare reimbursements, facilities used various strategies to reduce costs, such as decreasing the length of each dialysis treatment, reducing staffing levels, and substituting technicians for higher-paid nurses. [2] There was suggestive, but not conclusive, evidence that such changes in response to decreased reimbursement resulted in increased mortality and morbidity. [2] It is plausible - but unproved - that for-profit facilities may have applied these or similar measures more aggressively than not-for-profit facilities, with a negative effect on the quality of care provided to patients. The suggestion that for-profit facilities were less likely than not-for-profit facilities to refer patients for transplantation in order to retain revenue from dialysis is wholly speculative. It is conceivable, as Garg et al. suggest, that because of the reduction in staffing levels, less attention was paid to educating patients about the advantages of transplantation.

The Medicare ESRD program was also expected to ensure equity in the availability of dialysis and transplantation to all beneficiaries. Before the program began, the capacity of dialysis facilities was far less than was needed. At that time, well-educated white men were overrepresented among patients undergoing long-term dialysis. After the Medicare program provided funds to treat nearly all patients with ESRD, proportionately more members of minority groups, women, and patients with relatively less education were included; the population undergoing long-term dialysis reflected more closely the population with the disease. [9] Similar equity in access to kidney transplantation, however, has yet to be achieved. Cadaveric kidneys are a scarce resource; their number is insufficient to provide transplants for all patients who are candidates for transplantation. A number of studies have shown convincingly that minorities, women, and persons with low income have reduced access to kidney transplantation. [10-13]

The report by Ayanian et al., [14] also in this issue of the Journal, evaluates the possibility that the difference between blacks and whites in access to transplantation is due to a difference in the preferences of patients; they conclude that it is not. Blacks were only slightly less likely than whites to want a transplant (by about 4 percentage points) and were slightly less likely to be very certain about their preferences (by about 10 percentage points). Statistical analyses with adjustment for many possible confounding factors indicated that these differences accounted for only a small fraction of the much larger differences in the rates of referral for evaluation at a transplantation center (a difference of about 23 percentage points, with a lower rate for blacks) and of placement on a waiting list or receipt of a transplant (a difference of about 28 percentage points, with a lower rate for blacks).

A racial difference in access to kidney transplantation has been documented for more than a decade. [10-13] It is part of a general pattern in the United States, in which blacks have less access than whites to numerous effective clinical treatments, including cardiac catheterization, cardiovascular surgery, and as recently reported in the Journal, treatment for early-stage lung cancer. [15] Such differences, whether they are due to bias, to difficulties in communication between black patients and their physicians, who are in most cases white, or to other unknown factors, are especially unconscionable in a program paid for largely by the U.S. government. Physicians caring for patients with ESRD must keep this issue in mind as they advise their patients. The federal government should expect dialysis programs to meet reasonable standards for equitable access to transplantation for all patients, regardless of race, sex, or social status. The government should also encourage and facilitate research on methods to overcome the persistent inequity in its ESRD program.

Unlike Garg et al., Ayanian and associates did not find that access to transplantation differed among patients treated in for-profit dialysis facilities and patients treated in not-for-profit facilities. Also, unlike previous studies, [12,13] the study by Ayanian et al. did not show a significant difference between the sexes in access to transplantation. Several differences between the studies could account for the discrepant findings. These include the populations studied, how transplants from living related donors were considered, and the definitions of access to dialysis and transplantation. These differences underline the difficulty in drawing firm conclusions about critical issues in dialysis and transplantation with regard to policy and care, even from studies undertaken carefully, such as those by Garg et al. and Ayanian et al.

All providers have been under pressure to maintain the quality of dialysis treatments despite the progressive ratcheting down of reimbursement. On the basis of a review of information available in 1991, an Institute of Medicine committee on the ESRD program recommended periodic adjustments in the amount reimbursed for a dialysis treatment, as is done for other treatments reimbursed by Medicare. [2] The Medicare Payment Advisory Commission recently recommended an increase of 2.4 to 2.9 percent. These recommendations have not been implemented by the Health Care Financing Administration. Further research is needed to determine whether the quality of care has been eroded by decreasing inflation-corrected reimbursement in both not-for-profit and for-profit facilities.

The increased mortality among patients treated at for-profit facilities, reported by Garg et al., and the lower quality of care in such facilities, reported by other investigators, [5-7] suggest that, faced with the same financial pressures, for-profit facilities respond differently from not-for-profit facilities - to the detriment of patient care. These findings warrant a thorough review of practices not only by for-profit facilities but also by the nephrologists responsible for their patients.

The influence of ownership is part of the broader issue of quality assurance in the ESRD program. [16] This issue has been discussed by professional societies and the federal government for many years, and limited progress has been made in establishing a system-wide quality-assurance program. There has been a reluctance to impose standards of quality because of the limits of current knowledge as well as fear of the punitive use of standards and of federal prescription of clinical practice. The government, with the advice of expert panels, must use knowledge about the influence of ownership in developing standards of quality for the ESRD program, and these standards should be modified to reflect new data as they accumulate.

Norman G. Levinsky, M.D.

Boston University Medical Center; Boston, MA 02118

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Medical Progress: Renal Transplantation in Black Americans

[Review Article]

Young, Carlton J.; Gaston, Robert S.

From the Department of Surgery, Division of Transplantation (C.J.Y., R.S.G.), and the Department of Medicine, Division of Nephrology (R.S.G.), University of Alabama at Birmingham, Birmingham. Address reprint requests to Dr. Gaston at the Division of Nephrology, 625 THT, University of Alabama at Birmingham, 1530 3rd Ave. S., Birmingham, AL 35294-0006, or at rgaston@nrtc.dom.uab.edu.

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Despite remarkable social changes in the United States during the past century, issues related to race and ethnic background continue to permeate public discourse regarding health care. [1,2] The influence of race on the delivery of care for end-stage renal disease remains especially controversial because of two seemingly unrelated factors. First, the incidence of kidney failure among black Americans is disproportionately high, resulting in the demographic anomaly of black overrepresentation in the population with end-stage renal disease. Second, passage of the Social Security Amendments of 1972 entitled virtually all people in the United States with end-stage renal disease to Medicare-funded dialysis or transplantation (with implicit guarantees of equal access to optimal treatment). [3]

Since this topic was last reviewed in the Journal, [4] debate has intensified. [5,6] In this article, we summarize the effect of multiple interrelated scientific and political factors on the care of blacks with kidney failure. We do not address the special issues pertinent to other minority populations, such as Hispanic Americans and Asian Americans. End-stage renal disease is less prevalent in these groups. [7]

End-Stage Renal Disease in Black Americans

Since the 1970s, it has been noted that black Americans are at significantly greater risk of end-stage renal disease than whites. [8-11] Currently, although they represent less than 13 percent of the general population, blacks make up almost a third of those with end-stage renal disease. [7] The incidence of end-stage renal disease in blacks in 1997 (873 per million) was over four times that in whites (218 per million), and the prevalence was almost five times as great (3579 per million vs. 803 per million). Although hypertension is the most commonly identified cause of kidney failure among blacks, those with almost any renal disorder are at greater risk than whites of ultimately requiring dialysis or transplantation. [12,13]

An editorial in the Economist succinctly framed the debate regarding race and end-stage renal disease: "Perhaps the most important question is: what can be done to lower black Americans' high rates of catastrophic kidney disease?" [14] The prevalence of hypertension among blacks in America remains the highest of any subpopulation in the world - a paradox, given the typically low blood pressure documented in sub-Saharan Africans. [15] There is mounting evidence that both environmental and genetic causes have a role: excess salt intake, superimposed on a genetic predisposition to salt retention, may lead to low-renin hypertension. [12,16,17]

Other research indicates a tendency among black Americans for hypertension to have deleterious effects on renal function, even if blood pressure is well controlled. [11,12,18] Recent studies documenting racial differences in the expression of transforming growth factor (beta), angiotensin-receptor genotypes, and endothelial-dependent vasodilatation may provide a scientific basis for such observations. [19-22] Added to these physiological variables are the socioeconomic and educational disadvantages often encountered by American blacks, many of whom never receive care for their hypertension before the development of irreversible kidney failure. [1,2,10,23] Despite ongoing efforts to gain a better understanding of hypertensive renal disease in blacks, end-stage renal disease in America is likely to affect blacks disproportionately for the immediate and foreseeable future. [24]

Therapy for End-Stage Renal disease in Black Americans

In the 1970s, dialysis was considered the optimal treatment for patients with chronic renal failure. [25] Within a decade, however, improving outcomes of renal transplantation began to challenge this assumption. [9] Currently, over 90 percent of transplant recipients maintain graft function for at least a year, and the half-life for cadaveric kidneys (the length of time for which 50 percent of grafts that survive for 1 year remain functional) now exceeds 10 years. [7] In addition, renal transplantation reduces mortality, improves the quality of life, and is less costly than dialysis. [26-28] Cognizant of these advantages, the federal government supports organ procurement, reimburses most costs associated with renal transplantation, and requires that all patients with end-stage renal disease undergo evaluation for transplantation. [3,29]

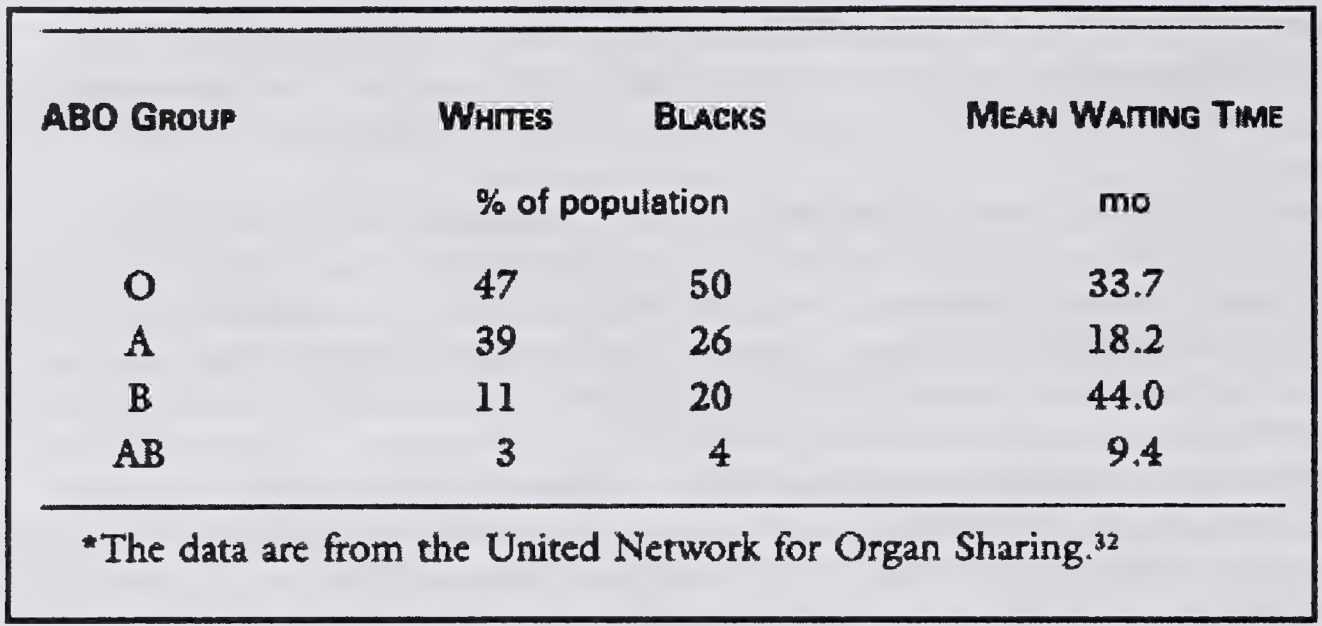
Since blacks may live longer on dialysis than whites, some have suggested that dialysis should be the preferred therapy for end-stage renal disease in black patients. Indeed, the increased prevalence of end-stage renal disease among blacks may partially reflect this racial difference in survival on dialysis. [7,30,31] However, data from the U.S. Renal Data System indicate that the advantages of transplantation over dialysis, including significant prolongation of life expectancy, are not limited by race or ethnic background. [6,28] As early as 1988, Eggers noted that black patients with end-stage renal disease had less access to transplantation than whites. [9] The facts underlying this critical observation remain largely unchanged: a black patient with end-stage renal disease is less than half as likely as a similar white patient to receive a kidney transplant. [7] Black patients make up 37 percent of the U.S. population undergoing dialysis but receive only a quarter of cadaveric kidneys and 14 percent of kidneys from living donors. [7,32] In addition, the median waiting time for a cadaveric kidney is almost twice as long (1185 vs. 605 days) for a black candidate as for a white one. [32] These differences are not evident in the transplantation of other solid organs. Given the demographic characteristics of end-stage renal disease, they seem perversely paradoxical.

After the onset of end-stage renal disease, the process leading to transplantation is complex, and racial disparity appears very early. Black patients are less likely than whites to be identified as candidates to receive transplants and, ultimately, to appear on waiting lists for transplants within the first year of Medicare eligibility; this discrepancy is not evident for other minority groups. [33,34] Because Medicare has required, since the early 1990s, that all patients undergoing dialysis be evaluated for transplantation, one might expect racial differences to be waning. As documented by Epstein and coworkers elsewhere in this issue of the Journal, however, this is not the case. [35] Blacks accounted for only 28 percent of additions to waiting lists for transplantation in 1997. [32] In a 1998 study, Kasiske and colleagues found that whites were more than twice as likely as blacks to be wait-listed before they begin dialysis. [36] Ayanian et al. found that black patients with end-stage renal disease, once they were fully informed of their options, preferred transplantation over dialysis as often as whites but were significantly less likely to proceed rapidly to transplantation. [5]

Even after referral for evaluation for transplantation, blacks remain at a disadvantage. Ayanian and colleagues found that referred blacks were less likely than whites to appear on waiting lists or undergo transplantation (84 percent of whites vs. 70 percent of blacks), a discrepancy attributed to place of residence, educational levels, overall health status while undergoing dialysis, and associated medical conditions. [5] Indeed, the evaluation process may be part of the problem. Evaluation for transplantation requires potential candidates to complete a complex array of outpatient interviews and medical screenings - a daunting task for many patients with end-stage renal disease who have limited resources. At our institution, where referral results in an inpatient evaluation lasting two or three days, 80 percent of evaluated whites and 76 percent of evaluated blacks proved acceptable candidates for a transplant. [37]

Once candidacy is established, blacks are substantially less likely than whites to identify a potential living donor. [37,38] Potential black donors are more likely to be excluded because of previously undiagnosed coexisting conditions, such as glucose intolerance or hypertension. [37] At our institution, only 13 percent of acceptable black candidates for transplantation, as compared with 33 percent of whites, ultimately received a kidney from a living donor; these findings are almost identical to those reported nationally. [32,39] Although better education and surgical advances (such as laparoscopic nephrectomy) might increase the overall numbers of living donors, factors such as preexisting medical conditions in family members may limit the effect of these improvements among black patients with end-stage renal disease. [38,40]

With fewer living donors available, black candidates for transplantation are more dependent on cadaveric kidneys. [32,41,42] Once again, socioeconomic disadvantage is important: when a kidney becomes available, black candidates may be more difficult to contact and less able to travel to the transplantation center in a timely fashion. [43] Most researchers agree, however, that immunologic variables are of greater importance. Given the medical necessity for compatibility of blood types and the allocation policy of the United Network for Organ Sharing (UNOS), which requires ABO identity, black candidates are at a disadvantage owing to their higher frequencies of ABO types that are associated with longer waits (Table 1). [32] On the other hand, Kallich et al. found that within blood groups, blacks waited from 23 percent longer than whites (for type O) to 60 percent longer (for type B); this difference implies that ABO differences alone do not explain the racial discrepancy. [34]



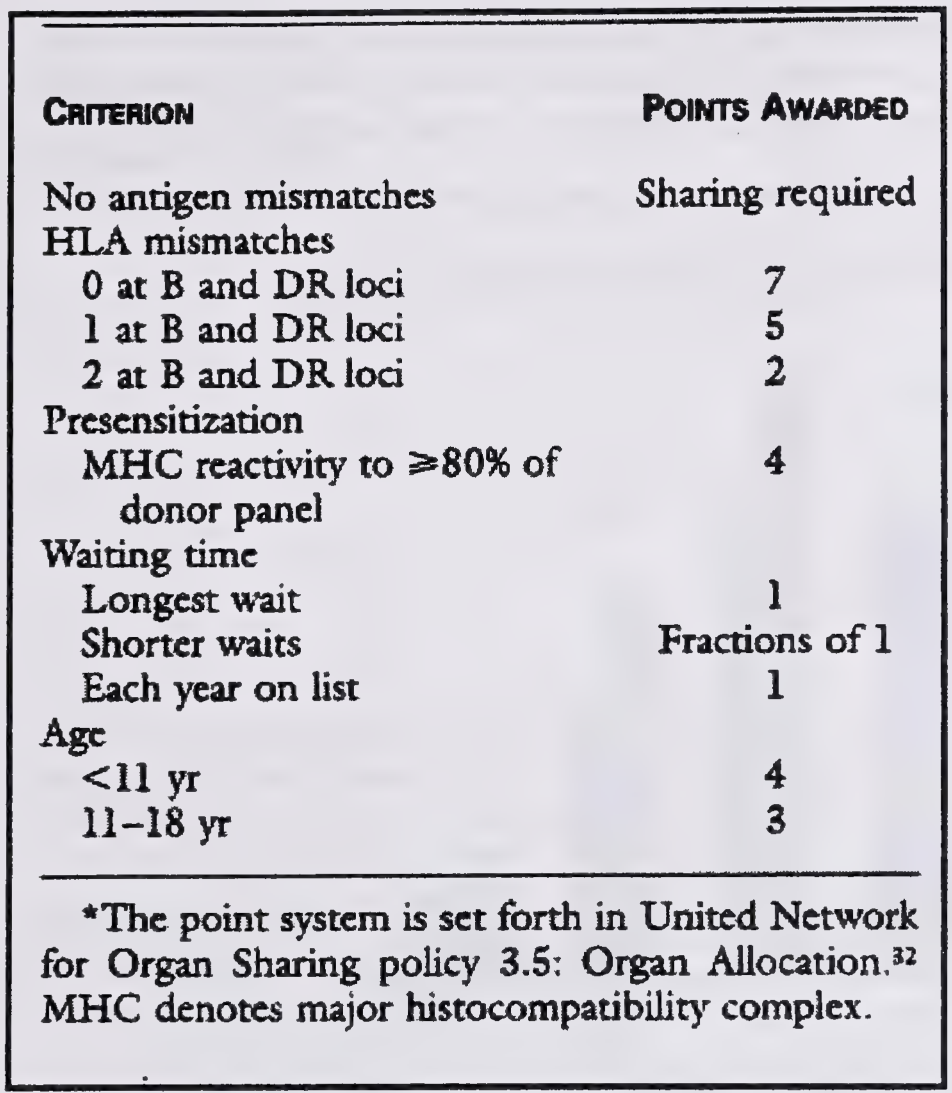
ABO GROUP	**WHITES**	**BLACKS**	**MEAN WAITING TIME**
	% of population		mo
O	47	50	33.7
A	39	26	18.2
B	11	20	44.0
AB	3	4	9.4

*The data are from the United Network for Organ Sharing.[32]

Table 1. Racial Distribution of ABO Blood Groups and Mean Waiting Time for Cadaveric Renal Transplantation According to ABO Blood Group.

In addition, black candidates for transplantation are more likely to have substantial anti-major-histocompatibility-complex (MHC) reactivity (presensitization) than similar whites, resulting in positive cross-matching that precludes transplantation from a given donor. [34,44] Patients with end-stage renal disease who are presensitized to 20 percent or more of potential donors wait substantially longer than others for transplantation; a black patient receiving a cadaveric transplant is 40 percent more likely than a white patient to have met this criterion. [32] Some investigators attribute differences in waiting times between blacks and whites almost entirely to presensitization. [34]

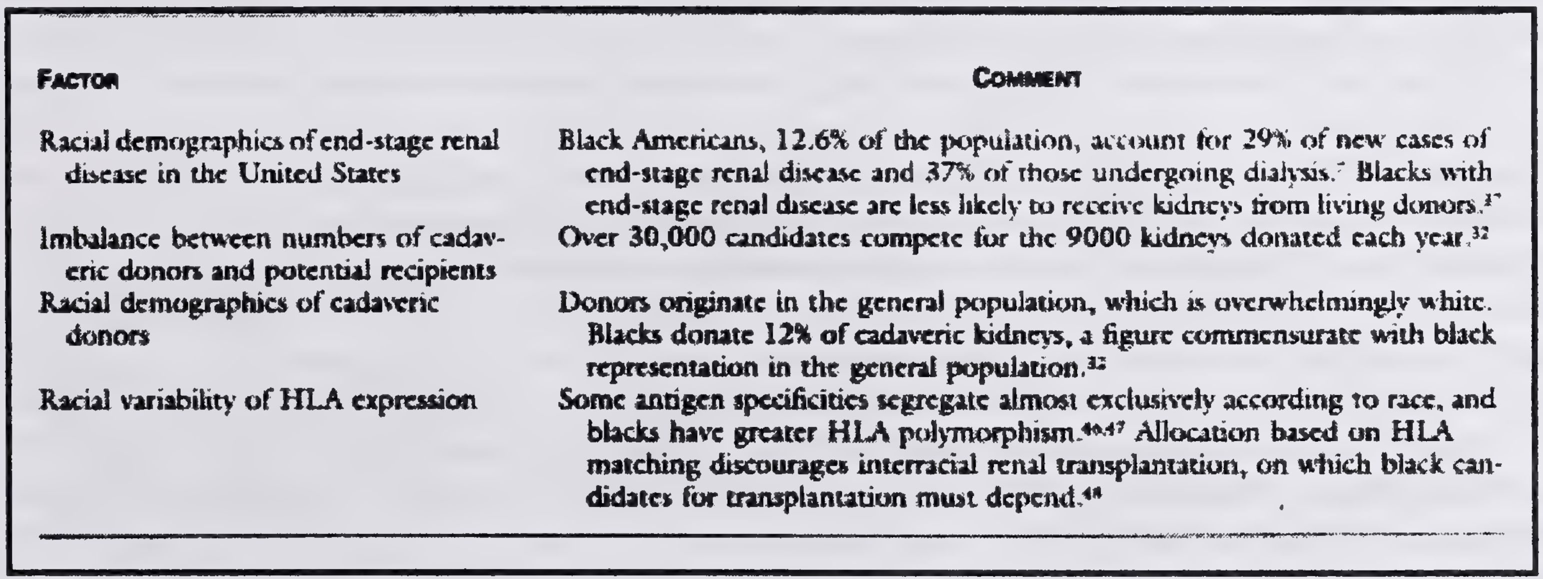
Another important immunologic variable is the relative weight of HLA matching in the UNOS allocation algorithms (Table 2). Wait-listed candidates for transplantation accumulate points. When a kidney becomes available, the candidate with the most points is designated to receive the organ. As a result of the assumption that similarity in HLA-antigen expression (matching) between donor and recipient optimizes outcomes, matching is the predominant variable determining the allocation of cadaveric kidneys. [45] Several demographic and immunologic factors combine to place black Americans at a disadvantage (Table 3). The net result, however unintentional, is preference for white candidates for transplantation.



CRITERION	POINTS AWARDED
No antigen mismatches	Sharing required
HLA mismatches	
0 at B and DR loci	7
1 at B and DR loci	5
2 at B and DR loci	2
Presensitization	
MHC reactivity to ≥80% of donor panel	4
Waiting time	
Longest wait	1
Shorter waits	Fractions of 1
Each year on list	1
Age	
<11 yr	4
11–18 yr	3

*The point system is set forth in United Network for Organ Sharing policy 3.5: Organ Allocation.[32] MHC denotes major histocompatibility complex.

Table 2. Current Point System of the United Network for Organ Sharing for the Allocation of Cadaveric Kidneys in the United States.



FACTOR	COMMENT
Racial demographics of end-stage renal disease in the United States	Black Americans, 12.6% of the population, account for 29% of new cases of end-stage renal disease and 37% of those undergoing dialysis.[7] Blacks with end-stage renal disease are less likely to receive kidneys from living donors.[37]
Imbalance between numbers of cadaveric donors and potential recipients	Over 30,000 candidates compete for the 9000 kidneys donated each year.[32]
Racial demographics of cadaveric donors	Donors originate in the general population, which is overwhelmingly white. Blacks donate 12% of cadaveric kidneys, a figure commensurate with black representation in the general population.[32]
Racial variability of HLA expression	Some antigen specificities segregate almost exclusively according to race, and blacks have greater HLA polymorphism.[46,47] Allocation based on HLA matching discourages interracial renal transplantation, on which black candidates for transplantation must depend.[48]

Table 3. Demographic and Immunologic Factors That Combine to Place Black Candidates at a Disadvantage in the Allocation of Cadaveric Kidneys for Transplantation.

Lazda and Blaesing recognized this trend over a decade ago: only rarely did interracial transplantation involve matching for more than three HLA alleles (out of a possible six). [48,49] Reviewing data from the National Marrow Donor Program, Beatty and coworkers found that blacks were only 28 percent as likely as whites to find a completely HLA-matched donor among 500,000 potential donors. [46] The clinical implications are predictable. At our institution, despite a waiting list containing more than 60 percent blacks, only 1 of 33 fully matched cadaveric kidneys went to a black recipient. [50] Nationally, 14 percent of all cadaveric kidneys are transplanted into fully matched recipients, of whom 90 percent are white and only 9 percent black. Between 1987 and

1995, black patients, making up approximately one third of the national waiting list, received only 6 percent of fully matched kidneys (Figure 1). Conversely, 30 percent of partially or fully mismatched kidneys go to black recipients, approximating the frequency with which blacks appear on the waiting list. [51,52]

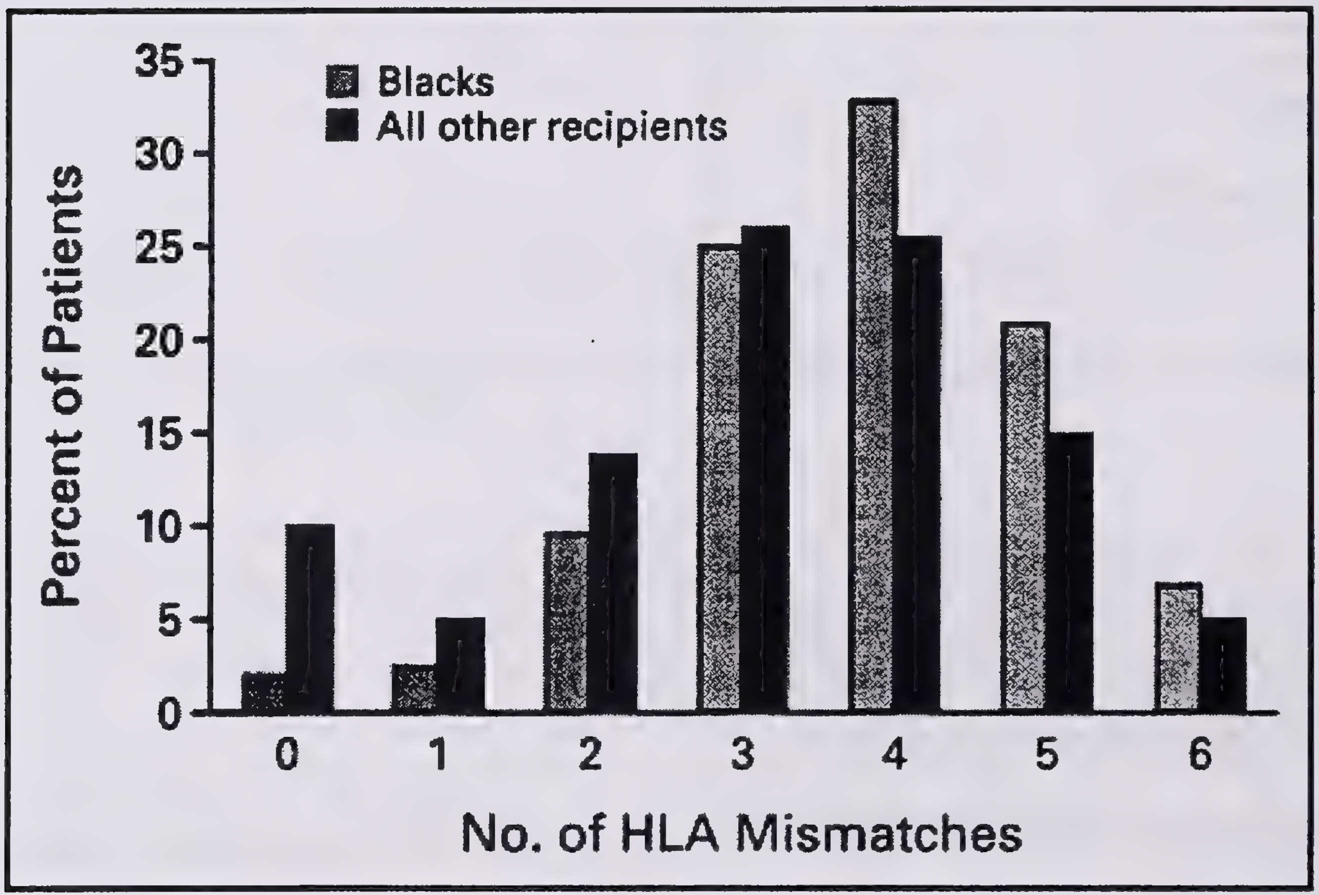
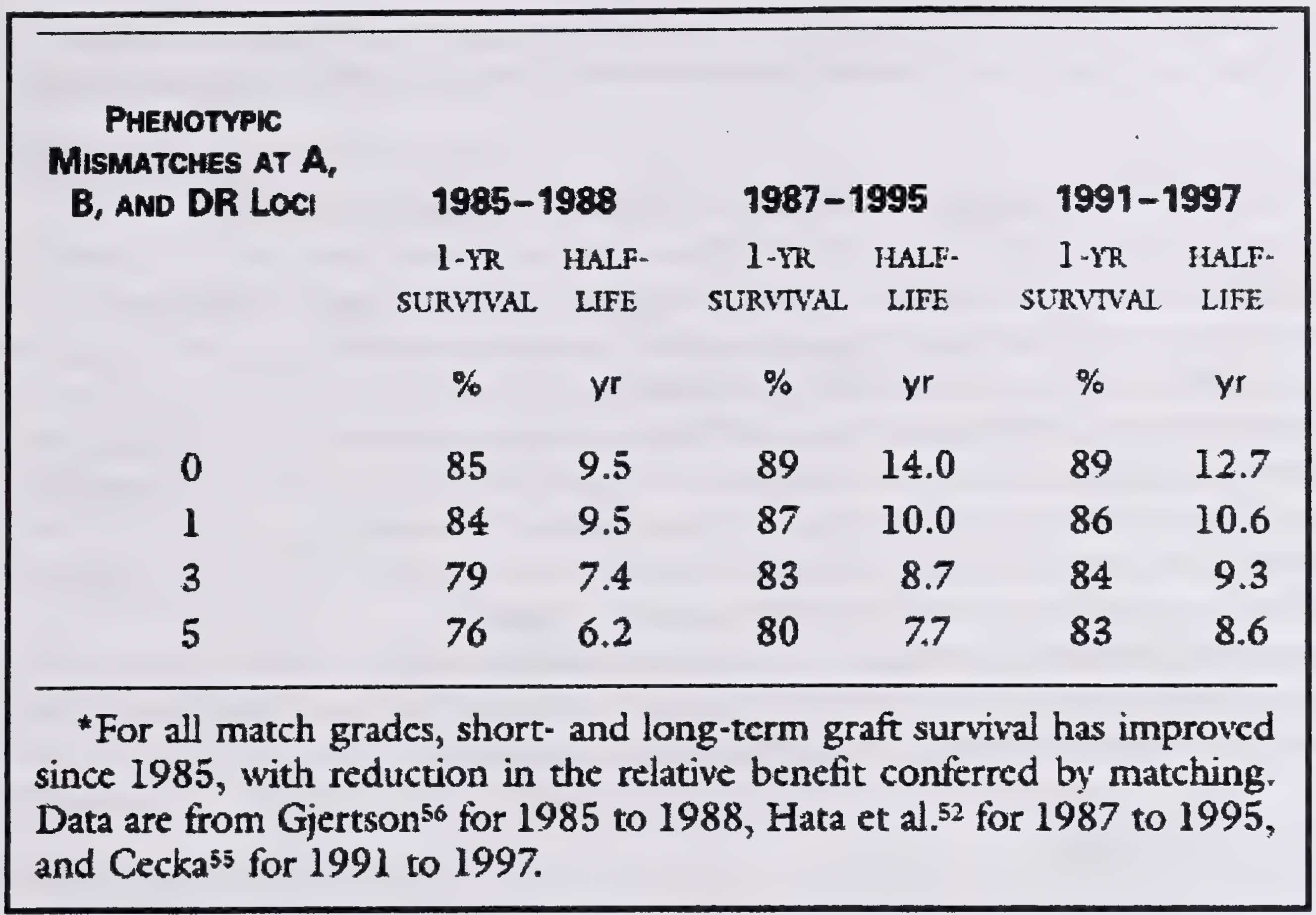


Figure 1. Racial Distribution of 31,291 Transplantations of Cadaveric Kidneys in the United States between 1991 and 1995 According to A, B, and DR Mismatching. Fewer than 5 percent of kidneys received by blacks had no mismatches or one mismatch, in contrast to more than 15 percent of those received by members of other racial groups. More than 50 percent of black patients received a kidney with at least four mismatches [51].

Even proponents of the current allocation system concede that there is racial disparity. [53,54] Disagreement focuses on what benefits are derived despite this disparity. Advances in clinical transplantation have reduced the effect of matching on allograft survival (Table 4). [52,55-57] In the 1980s, when most of the current point system originated, improved HLA compatibility between donor and recipient provided a demonstrable incremental benefit. Now, investigators have estimated that the overall national effect of optimal HLA matching would be to improve graft survival by 1 to 2 percent. [42,58] For black recipients, the benefits of HLA matching are even more elusive. Early reports documented no statistical benefit of matching among black Americans - a finding attributed to the difficulty of obtaining enough good matches for meaningful analysis. [53,54] Current data indicate a benefit for black Americans of 5 to 6 percent (in graft survival at 3 years) in the few patients able to receive completely matched grafts, as well as improvement in the half-life of allografts from 5.4 to 8.4 years (which is still less than the 9.7 years expected for mismatched kidneys in white recipients). [51,52] Overall, the primary benefit of the current allocation system is to the predominantly white recipients of completely matched grafts; partial matches have a marginal effect on outcomes, especially among black recipients.



Phenotypic Mismatches at A, B, and DR Loci	1985–1988		1987–1995		1991–1997	
	1-yr survival	half-life	1-yr survival	half-life	1-yr survival	half-life
	%	yr	%	yr	%	yr
0	85	9.5	89	14.0	89	12.7
1	84	9.5	87	10.0	86	10.6
3	79	7.4	83	8.7	84	9.3
5	76	6.2	80	7.7	83	8.6

*For all match grades, short- and long-term graft survival has improved since 1985, with reduction in the relative benefit conferred by matching. Data are from Gjertson[56] for 1985 to 1988, Hata et al.[52] for 1987 to 1995, and Cecka[55] for 1991 to 1997.

Table 4. Effect of HLA-Antigen Matching on Outcomes of Primary Cadaveric Renal Transplantation According to Years during Which Transplantation Occurred.

Can racial disparity in access to renal transplantation be attenuated? More timely referral for treatment of end-stage renal disease and better education of potential donors and recipients are likely to be of benefit. However, the problems associated with ABO types and presensitization will probably be more daunting. Although eliminating the donor shortage would obviously remedy any racial disparities in the allocation process, there is no indication of an impending deluge of donated organs. Increasing the number of black donors might theoretically provide more well-matched kidneys for black candidates for transplantation. [54,59] However, given the prevalence of end-stage renal disease and HLA polymorphisms among black Americans, this approach seems unlikely to resolve the problem of access. [41,60] Indeed, because of ongoing efforts to promote minority donation, the percentage of black donors now corresponds to the proportion of blacks in the general population. [32,61]

Inasmuch as the current UNOS algorithm perpetuates racial disparity, major changes may be necessary. Mandatory sharing of completely matched kidneys should continue; it improves transplantation outcomes and, despite identifiable adverse effects on access for blacks, removes relatively few organs from the overall pool. [41,52,62] The allocation of points for partial matching is less defensible. A 1995 analysis confirmed that matching points were accumulated disproportionately by whites and were being awarded for matching that produced outcomes no better (two mismatches) or worse (three mismatches) than the national average. [45] In response, the algorithm was modified to its current form (Table 2); the effect of these modifications on minority access should be reassessed. [63] A recent regional study involving the New England Organ Bank showed that the elimination of points for partial matching improved access for minority groups without compromising outcomes. [64]

Other modifications are possible. Currently, UNOS allows local variance based on the concept of "acceptable mismatches" that, at least theoretically, preserve the benefits of matching while offering more equitable allocation. [53] Although some are skeptical about the potential benefit of such an approach, prospective evaluations are under way. [51,65] Alternatively, in the light of increasing recognition of the influence of nonimmunologic factors (particularly early graft function and the donor's age) on long-term survival, it may be time to formulate a new approach to organ allocation. [66-68]

Outcome of Renal Transplantation in Black Americans

After receiving renal transplants, black patients with end-stage renal disease fare substantially worse than whites or members of other minority groups; this discrepancy was first noted by Opelz and coworkers and repeatedly confirmed in a litany of concordant studies. [8,32,55,56,69-72] The earliest reports indicated that racial differences appeared shortly after transplantation, with more early rejection and graft loss in blacks and graft survival that was 8 to 10 percent lower at one year. The half-life of grafts in blacks was 30 to 40 percent of that expected in whites. [71,73,74] The pattern has changed, however; rates of early rejection in blacks are lower than they were, and graft survival one year after transplantation no longer differs according to race. [55,70,72,73] Disappointingly, these short-term improvements have not translated into long-term success, as blacks remain at greater risk for late graft loss, with a persistently shorter graft half-life than whites. The potential explanations for these observations are varied and unproved.

Nonimmunologic Variables

An early explanation for racial disparity in outcomes, termed the "center effect," held that black patients were more likely to receive transplants at centers where the results were poor for all patients. [71,74,75] However, the documentation in a 1994 study that blacks fared worse than whites within each grade of transplantation center made it difficult to attribute inferior outcomes in blacks to inferior care. [76]

Hypertension, a key factor predisposing black Americans to end-stage renal disease, might also contribute to poorer outcomes after transplantation. [77] Cosio and coworkers linked long-term graft failure in blacks to poorly controlled hypertension. [78] They found that elevated blood pressure after transplantation correlated with shorter half-lives of grafts in blacks but not in whites and that the half-lives among normotensive whites and blacks were identical. Another study documented a correlation between poorly controlled hypertension before and after transplantation and renal-allograft dysfunction. [79] Although these reports indicate that there is a link between hypertension and graft failure in blacks, they do not establish a cause-and-effect relation.

Economic hardship predicts poorer transplantation outcomes. Kalil and associates found a strong association between low family income and return to dialysis. [80] A more recent analysis of renal-transplantation outcomes according to ZIP Code documented a significantly greater risk of late graft loss in lower-income areas. [81] Butkus and coworkers reported that patients without private insurance at the time of transplantation, who were more often blacks, were at increased risk for allograft loss. [82] Conversely, in the military, with identical access to care across ethnic and socioeconomic lines, there is no racial difference in graft survival. [83]

The link between socioeconomic status and allograft failure may reside in the capacity of patients to adhere to complex and expensive medical regimens over prolonged periods, since noncompliance with medication increases the risk of graft loss. [84-86] At our institution, noncompliance and late graft loss are closely linked, especially among black patients. [87] Schweizer and colleagues found that noncompliance with regard to medications and office visits was a significant predictor of graft loss in renal-transplant recipients and occurred more often among blacks than among whites; however, after correction for socioeconomic status, racial differences vanished. [86] There appears to be a strong relation among socioeconomic status, educational background, and compliance with treatment. Indeed, it has been suggested that these variables may be the key factors that account for worse long-term outcomes in black transplant recipients. [88,89]

Immunologic Variables

Although it is tempting to attribute reduced graft survival in black recipients to poorer HLA matching, several lines of evidence indicate otherwise. First, a link between better matching and better outcome is difficult to document in blacks. [51,54,90] Second, Asian-American recipients who are as poorly matched with their organ donors as black Americans have graft survival equal or superior to that of whites. [52,91] Third, multivariate analyses have repeatedly failed to link differences in HLA matching to racial discrepancies in outcomes. [69,73,78,92] Finally, for each grade of matching in cadaveric transplantation, blacks fare worse than whites, particularly over the long term. [51,72] For instance, three-year graft survival in black recipients of cadaveric kidneys with a single mismatch is 69 percent, as compared with 79 percent in white recipients. This difference has been attributed to more frequent HLA polymorphism in blacks (e.g., serologic identification of HLA-A23 may have different implications in blacks and whites). [47] However, even kidneys from genetically identical living donors, with nonpolymorphous, one- and two-haplotype matches fare significantly worse in blacks than whites. [70,89]

Immunologic determinants other than matching also differ between blacks and whites. Racial mismatching of minor-blood-group (e.g., Lewis and Duf fy) antigens has been postulated to have some effect on outcome. [93,94] As noted earlier, blacks are more likely than whites to have presensitization to HLA antigens. [55,72] Although delayed graft function may be thought of as a nonimmunologic variable, it clearly imparts immunologic risk. [95,96] Overall, delayed graft function reduces one-year graft survival by almost 20 percent, and it has a similar effect on long-term outcome. [91] Black recipients of cadaveric kidneys are 40 percent more likely than whites to have delayed graft function and compromised graft survival. [72]

Acute rejection occurs more commonly in blacks than in whites, and its prevention may require more intense immunosuppression. [72,73,97,98] Although some maintain that racial differences in the pharmacokinetics of immunosuppressive drugs explain these findings, [98-100] there are contradictory data. [97,101] Black recipients also have an increased risk of acute rejection and graft loss in trials of the reduction of immunosuppression. [102,103] In a recent study, withdrawal of corticosteroids three months after transplantation in patients who were also receiving cyclosporine and mycophenolate mofetil resulted in substantially more episodes of acute rejection in blacks than whites. [104] Kerman and colleagues attributed such increased risks among blacks to immunologic hyperresponsiveness, with cells from blacks having stronger responses than cells from whites to a panel of nonspecific immunologic tests (mixed lymphocyte culture, T-cell subgroup analysis, and spontaneous blastogenesis). [44,105] More recently, other investigators have reported increased expression of costimulatory molecules in peripheral-blood mononuclear cells and overexpression of transforming growth factor (beta) (but not interleukin-6 or tumor necrosis factor (alpha)) in blacks, suggesting potential mechanisms by which immunologic responses might be more likely to result in graft failure. [21,106]

Integrating Immunologic and Nonimmunologic Causes of Graft Loss

The racial disparity in the clinical outcome of transplantation probably reflects the interaction of multiple variables. In recent years, better immunosuppression has abolished differences between blacks and whites in early outcome, and racial differences in acute rejection and graft loss during the first year after transplantation are now negligible. [32,73,89] Beyond the early post-transplantation period, progressively greater differences emerge as immunologic risk may be augmented by other variables. If noncompliance is more common among the economically disadvantaged (who are disproportionately black), the presence of immunologic hyperresponsiveness among black recipients (regardless of its underlying basis) may increase the risk of graft loss. Thus, similar socioeconomic or compliance-related factors may have more severe consequences in blacks than in whites. [87]

This hypothesis has been tested, albeit retrospectively. When the loss of Medicare benefits for immunosuppressive drugs forced a cohort of impoverished patients to discontinue cyclosporine treatment, only the black recipients had rejection and graft loss. [102] Subsequently, when similarly disadvantaged patients received cyclosporine through a program to provide care to indigent patients, demonstrable adverse outcomes disappeared among black recipients. [107] Recent analysis of information from the U.S. Renal Data System found that the extension of Medicare coverage for immunosuppressive therapy from one to three years after transplantation had the greatest benefit among those in lower socioeconomic strata. [81] Further extension of Medicare benefits for immunosuppressive drugs might have a similar beneficial effect. [29]

Conclusions

The evolution of renal-replacement therapy in the United States has been a remarkable accomplishment, with efficacy and scope far exceeding the original expectations. However, formidable hurdles remain, particularly for black Americans. We must explain why blacks have end-stage renal disease so frequently, and we must develop ways to intervene earlier in the process. We must improve outcomes for black transplant recipients, whether the remedy is as simple as improved availability of immunosuppressive drugs or as complicated as defining currently uncharacterized immunologic pathways. Most important, we must ensure that race no longer limits the access of the most direly affected subgroup of patients with end-stage renal disease to optimal therapy.

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MASSACHUSETTS
GENERAL HOSPITAL

Joseph R. Betancourt, MD, MPH
Senior Scientist, Institute for Health Policy
Program Director, Multicultural Education
Department of Medicine & Health Policy, HMS

Tel: 617 724-9713
Fax: 617 724-4738

50 Staniford Street, 9th Floor
Boston, Massachusetts 02114
E-mail: jbetancourt@pol.net

PARTNERS

INSTITUTE OF MEDICINE REPORT
"UNEQUAL TREATMENT: CONFRONTING RACIAL AND ETHNIC DISPARITIES IN HEALTH CARE"

Honorable Chair and Members of the Joint Committee on Health Care, distinguished colleagues, and guests, I'd like to wish you all a good morning, and thank you for giving me the opportunity to testify on the important issue of racial/ethnic disparities in health care. My name is Joseph Betancourt and I am a researcher, educator, and practicing Internist at the Massachusetts General Hospital and Harvard Medical School. It is my distinct pleasure to provide brief comments on the recommendations for eliminating disparities as delineated in the Institute of Medicine Committee Report "Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care" was released earlier this year on March 20th, 2002, which I had the honor of co-authoring along with my 14 other Committee members.

As you've already been told, the fact that racial/ethnic minorities in this country receive poorer quality health care is undeniable and indisputable. The Institute of Medicine Report provides a blueprint for why and how we should address this issue, and highlights that eliminating racial/ethnic disparities in health care should not be marginalized, but instead an integral part of improving the quality of our health care system, and the health care of all Americans.

For starters, we need to raise awareness of this issue among health care providers, policymakers, and the public—we want to generate discussion, discourse and action. Recent surveys have shown that both physicians and patients aren't aware of the extent, nor the severity, of racial and ethnic disparities in health care in this country. There has been an understanding of the fact that minorities suffer from poorer health in this country, but this was almost exclusively seen as the result of poverty, poorer education, and lack of health insurance. We now have a solid evidence base to highlight the fact that racial/ethnic disparities exist *within* the health care system—and occur for minority patients who have insurance, and are of the same socioeconomic class as their white counterparts. This is the news we bring today, and the news we hope to disseminate. This is a critical first step, as we cannot address a problem that we don't acknowledge exists.

Increasing awareness can occur through several venues—including the lay press, mass media, through professional medical societies, and even in our

health care professional educational institutions, such as medical and nursing schools.

More specifically, we made several recommendations that speak to some of root causes that Dr. McGuire described.
For instance:

- We recommend interventions—perhaps through incentives—to strengthen the physician-patient relationship. Deep down, we felt that doctors and patients want the same thing—the best possible health outcome. We'd like a health care system that facilitates that goal…and assures that there is time for physicians and patients to communicate effectively, and develop a true relationship…and this includes interpreter services for patients with limited-English proficiency, when needed.

- We recommend improving our data collection systems so that we can more systematically collect race/ethnicity and more effectively identify disparities locally, and then implement strategies to eliminate them. This may require specific oversight, and nationally we recommended providing greater resources to the Office of Civil Rights to achieve this task.

- We encourage the use of evidence-based guidelines in the treatment of patients—we now have excellent science to inform us how to best manage a diabetic, for example, regardless of their race and ethnicity—and therefore, through the use of guidelines, we hope to remove any subjectivity in treatment of such patients based on physician discretion, and instead insure that all patients are getting the highest quality of care, regardless of their race, ethnicity, culture or class.

- We recommend redoubling our efforts to improve our health care workforce diversity. Currently, minorities comprise only 6-8% of all physicians in this country, despite making up close to 30% of the population. We feel that it is important to have a health care workforce that more closely reflects this nation's population. There are multiple benefits of diversity, including the sharing of thoughts and perspectives among providers about patients, their situations, and the communities they come from.

- We recommend cross-cultural education for health care providers, so that they have the tools and skills to better understand and care for patients from diverse backgrounds. This includes curricula on health care disparities, the clinical decisionmaking process (including strategies to avoid stereotyping), how to use an interpreter, and how to effectively communicate and negotiate across cultures. These can be incorporated into health professions training at medical schools, nursing schools, and as part of continuing education.

- We also recommend strategies to educate patients to be more active in the medical encounter, and to take responsibility for their health and their partnership with their doctor. Lack of empowerment or involvement in the medical encounter by minorities may stem for historical mistrust of the health care system, perhaps due to events such as the Tuskegee Syphilis Study, or due to cultural factors.

Are there competing interests in health care today? Absolutely. Are there competing interests for health care funding? Without a doubt. But we have the expertise, talent and technology to deal with the issue of racial/ethnic disparities in health care in a cost-effective manner. We need to work together—health policymakers, health care purchasers, health care providers, and patients—to address this issue. Ultimately, we can ill afford to have patients sustain complications of long term, treatable chronic conditions because we weren't able to provide the highest quality of care to all patients we come in contact with, regardless of their race, ethnicity, culture, class, or language proficiency. We can invest in strategies to deal with this problem now, or we will pay later.

In your capacity as legislators, you can address this issue by:

- Developing initiatives and regulations to strengthen data collections systems so that we systematically collect race and ethnicity data of patients, and effectively document and eliminate disparities at the state, local, and hospital level. This *is* legal, and there are national models that provide an example on how to go about this effort.

- Support efforts and programs that encourage minority recruitment into the health professions. For example, New York State has developed a

"Residency Incentive Pool" for excellence in graduate medical education. This program provides financial awards to residency programs that develop innovations, and has recently included efforts towards minority recruitment, and cross-cultural education, as part of its selection criteria.

- Assure that any debate regarding patient's bill of rights extend not just to private HMO enrollees, but to publicly funded HMO enrollees as well

- Reengineer health care professional reimbursement systems to reward the use of evidence-based clinical guidelines, continuity of care, and other strategies that strengthen the provider-patient relationship. This includes increasing reimbursement for health professionals who use interpreters, as these medical encounters classically take more time and should be compensated accordingly

As a researcher, educator, and practicing physician, I see the challenges of dealing with racial and ethnic disparities in health care everyday—there are many, and they are real. This should not preclude us from engaging in discourse, action, and identifying creative solutions to deal with the issue of racial and ethnic disparities in health care. If high quality of care in Massachusetts is our goal, there are no excuses—we have to find a way, and the time is now.

Thank You.

CURRICULUM VITAE
Date Prepared: May 7, 2002

PART I
DEMOGRAPHIC INFORMATION:

NAME: Joseph Raymond Betancourt, M.D., M.P.H.

ADDRESS: 15 Flagg Street, Cambridge MA 02138

PLACE OF BIRTH: New York, NY

EDUCATION AND TRAINING

Education:

1986-1990	Bachelor of Science, cum laude, University of Maryland Major: Biology; Minor: Spanish Literature
1990-1994	Doctor of Medicine, New Jersey Medical School
1997-1998	Masters in Public Health, Harvard School of Public Health Concentration: Health Care Policy

Postdoctoral Training:

1994-1997	Internal Medicine Internship and Residency, New York Hospital-Cornell Medical Center
1997-1998	Commonwealth Fund-Harvard University Fellowship in Minority Health Policy, Harvard Medical School

PROFESSIONAL APPOINTMENTS

Academic Appointments:

1997-1998	Instructor in Social Medicine, Harvard Medical School
1998-1999	Instructor in Medicine, The Weill Medical College of Cornell University
1999-2001	Assistant Professor of Medicine and Public Health, The Weill Medical College of Cornell University
2001-	Instructor in Medicine, Harvard Medical School

Hospital Appointments:

1998-2001	Assistant Attending Physician, The New York Presbyterian Hospital; Associate Director, The Center for Multicultural and Minority Health
2001-	Assistant Attending Physician, Massachusetts General Hospital; Director for Multicultural Education

Other Professional Positions, Major Visiting Appointments, and Community Service:

Professional Positions:

1999	Consultant on Development of Cross-Cultural Curriculum, Memorial Hospital-Brown University Medical School
2000	Consultant on Development of Cross-Cultural Curriculum, Grady Memorial Hospital-Emory Medical School
2001-	Consultant on Development of Cross-Cultural Education Module, Institute for Healthcare Improvement and US DHHS Bureau of Primary Health Care
2001-	Consultant on Defining Strategies to Eliminate Disparities in Hispanic Health, US DHHS Centers for Medicare and Medicaid Services
2001-	Consultant on Developing a Tool to Identify Medical Errors (and Cost Impact) due to Language Barriers, US DHHS Office of Minority Health
2001-	Consultant on Development of Standards for Cultural Competence Curricula, Association of American Medical Colleges

Community Service:

1993-1994	Community 2000; Hispanic Liaison to Community Outreach Health Project in Newark, New Jersey
1993-1994	ASPIRA Hispanic Health Professions Team; Recruitment and Retention Speaker
1994	National Marrow Donor Program; Organizer of Latino Bone Marrow Drive in New York City
1997	Fellowship of Primary Care Health Professionals; Internist to Medically Underserved Areas in Puerto Rico
1998	Bridges to Community; Internist to Public Health Mission in Nicaragua

AWARDS AND HONORS

1994	Biological Honors Research Program Scholar Award, University of Maryland
1997	David B. Skinner, M.D. Award for Administrative Stewardship, New York Hospital-Cornell Medical Center
2000	Top 12 Abstracts at the Association of Health Services Research Meeting 2000 for "Differences in Use of Hospital Procedures for Cerebrovascular Disease among Hispanic and Non-Hispanic Whites"

MAJOR COMMITTEE ASSIGNMENTS

1995-1997	Minority Housestaff Committee (Co-Founder), New York Hospital-Cornell Medical Center
1997	ASPIRA Task Force on Medical Education, New York
1997-1998	Sociedad Latina Youth Agency Board of Directors, Boston
1997-1998	Department of Health and Human Services Region 1 Latino Health Initiative
1998	Foundation for Accountability, Review for Consumer Education Materials
1998	Harvard AIDS Institute Latino AIDS Initiative
1998-2001	New York Hospital Community Health Plan Medical Management Committee
1998-	Centers for Disease Control National Expert Council for Diabetes Today Program
1999	Agency for Healthcare Research and Quality Expert Committee for the User Liaison Program on Cultural Competence
1999-	Office of Minority Health CLAS Federal Standards Project
1999-	Association of American Medical Colleges Diversity Project Team
1999-	Health Care Financing Administration QISMC Cultural Competence Measurement Set Review Panel
1999	Commonwealth Fund Cultural Competence Working Group
2000	Greater New York Hospital Association Racial/Ethnic Disparities Steering Committee
2000	New York Academy of Medicine Racial Disparities Expert Committee
2000	Merck Northeast Medicaid Managed Care Advisory Board
2000-	Aventis Latino Influencer Network
2000-2001	Weill Medical College of Cornell University International Committee
2000-	American Diabetes Association Assistance and Resources Project Team
2000	Agency for Healthcare Research and Quality Expert Committee for the User Liason Program on Racial and Ethnic Disparities in Health
2000-	Institute of Medicine Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health
2001-	Physicians for Human Rights Expert Committee on Racial and Ethnic Disparities in Health
2001-	American Board of Internal Medicine Expert Committee on Doctor-Patient Communication
2001	Agency for Healthcare Research and Quality Expert Committee on MEPS Analytic Improvement

2001-	World Health Organization International Expert Committee on Adherence to Therapies
2001-	Society of General Internal Medicine Education Committee
2001-	Institute of Medicine Committee for Guidance in Designing a National Health Care Disparities Report
2001-	Robert Wood Johnson Foundation Habamos Juntos Project; Chair, Scholars Network

PROFESSIONAL SOCIETY INVOLVEMENT

1997-	American College of Physicians
1997-	American Public Health Association
1997-	Academy of Health Services Research and Health Policy
1998-	Society of General Internal Medicine
1998-	National Hispanic Medical Association

EDITORIAL BOARDS

Referee for Peer-Reviewed Journals:

1999-	American Medical Association Journal Consortium
2000-	Annals of Internal Medicine
2001-	Medical Care

Reviewer for Conference Submissions:

1999	Abstracts for Society of General Internal Medicine Annual Meeting
2000	Co-Chair, Health Disparities Workshops, Society of General Internal Medicine Annual Meeting
2001	Co-Chair, Health Policy Workshops, Society of General Internal Medicine Annual Meeting

Editor Positions

1999	Co-Editor, Patient Care. Special Issue on Caring for Diverse Populations
2001	Associate Editor, Society of General Internal Medicine Forum
2002	Co-Editor, Public Health Reports. Issue on Racial/Ethnic Disparities in Health

PART II

A. Report of Research

1. Major Research Interests
    a. Racial and Ethnic Disparities in Health
    b. Impact of Cross-Cultural Education on Health Outcomes

c. Health Policy as related to Multicultural and Minority Populations

2. Narrative Description of Research

There is a robust literature describing significant racial and ethnic disparities in health outcomes and health care in the US. Among many potential root causes are the impact of social determinants, healthcare workforce, structural processes of care, and provider-patient communication in the medical encounter, on health outcomes. My primary research interest is to further elucidate root causes for disparities, and identify methods for intervention. These include both systemic initiatives as well as provider-based efforts such as cross-cultural education.

3. Research Funding Information

ACTIVE

Hispanic Health Services Utilization: Defining and Exploring Disparities
Principal Investigator: Joseph R. Betancourt, MD, MPH
Agency: Health Care Financing Administration
Date: August 1999-March 2002

Cultural Competence in Health Care: A Practical Synthesis for Multilevel Policy Implementation
Principal Investigator: Joseph R. Betancourt, MD, MPH
Agency: Commonwealth Fund
Date: May 2000-April 2002

"Worlds Apart" Cross-Cultural Documentary Video Project
Principal Investigator: Maren Monsen, MD; Stanford University, CA
Role: Consultant
Agency: Commonwealth Fund
Date: May 2000-April 2002

Eliminating Racial/Ethnic Disparities in Chronic Conditions
Principal Investigator: Mark Chassin, MD; Mount Sinai Medical Center, NY
Role: Consultant
Agency: Agency for Healthcare Research and Quality
Date: September 2000-August 2005

Understanding Racial Differences in Lung Cancer Treatment
Principal Investigator: Peter Bach, MD, MS; Memorial-Sloan Kettering Cancer Center, NY
Role: Co-Investigator
Agency: National Cancer Institute
Date: April 2001-March 2003

Development of a Program on Health Disparities and Cross-Cultural Health Care
Principal Investigator: Joseph R. Betancourt, MD, MPH
Agency: Pfizer
Date: July 2001

Improving Diagnosis and Treatment of Colorectal Cancer
Principal Investigator: Michelle van Ryn, PhD.; University of Minnesota, MN
Role: Consultant
Agency: US DHHS Veterans Affair Administration
Date: July 2001-June 2004

State Level Effects of Racial and Ethnic Characteristics on Access to Care
Principal Investigator: Joel Weissman, PhD
Role: Co-Investigator
Agency: The Commonwealth Fund
Date: November 2001-October 2002

Developing and Implementing a Cross-Cultural Curriculum Needs Assessment for Medical Residents
Principal Investigator: Joseph R. Betancourt, MD, MPH
Agency: Schwartz Center
Date: March 2002-September 2002

PAST
Development of Cross-Cultural Curriculum Patient Simulation Videos
Co-Principal Investigators: Joseph R. Betancourt, MD, MPH, Alexander R. Green, MD, and J. Emilio Carrillo, MD, MPH
Agency: MERCK and Company
Date: March-May 1999

Limitations of Disease Management Programs in Voluntary-Enrollment Medicaid Managed Care
Co-Principal Investigators: Joseph R. Betancourt, MD, MPH, Alexander R. Green, MD, and J. Emilio Carrillo, MD, MPH
Agency: Schering Plough
Date: April-June 1999

B. Report of Teaching

1. Local Contributions

a. Medical School Courses

Weill Medical College of Cornell University

1995-1996	Humanity and Medicine
1998-2001	Cross-Cultural Primary Care
1999-2001	Cross-Cultural Ethics

b. Graduate Medical Courses

Weill Medical College of Cornell University

1999	Public Health Modeling
1998-2001	Cross-Cultural Primary-Care
1998-2001	Politics and Health Policy

c. Invited Teaching Presentations

Harvard School of Public Health

1999	Establishing the Link between Cultural Competency and Racial/Ethnic Disparities in Health; Minority Health Policy Seminar Series
2001	Delivering Quality Care to Diverse Populations: An Evidence-Based Approach; Minority Health Policy Seminar Series
2001	Race, Ethnicity, Culture and Class; Survey Design Course, Clinical Effectiveness Curriculum

d. Invited Presentations

1. Developing Faculty Diversity. Harvard Medical School Department of Social Medicine, Boston, MA, April 1998
2. Challenges in Minority Health. Project Success Student Program of Harvard Medical School, Boston, MA, June 1998
3. Cross-Cultural Primary Care: A Patient-Based Approach. Brigham and Women's Transcultural Forum, Boston, MA, October 2000
4. Cross-Cultural Primary Care: A Patient-Based Approach. Brigham and Women's Transcultural Forum, Boston, MA, October 2001
5. "Not Me!": Racial/Ethnic Disparities in Health Care Massachusetts General Hospital Medical Grand Rounds, Boston, MA, November 2001

2. Regional, National, or International Contributions

1. Recruiting Latinos into Medical School: A 20th Century Crisis. Eleventh Hispanic Biomedical Congress, San Juan, PR, October 1996
2. Latino Leadership in Health Care: Preparing the Next Generation. National Hispanic Medical Association Conference, Washington, DC, March 1998
3. Latino Diabetes Program Structural Assessment: New England. Multicultural Health Summit, North Haven, CT, May 1998
4. Latino Diabetes Program Structural Assessment: New England. The Commonwealth Fund Annual Conference, Boston, MA, May 1998
5. Mentoring Minority Health Policy Researchers. Association for Health Services Research Annual Conference, Washington, DC, June 1998
6. Language, Culture, and Health: Cultural Competency Programs for Providers. National Coalition of Hispanic Health and Human Services, San Juan, PR, June 1998.

7. Models of Successful Latino Diabetes Program. Dimock Community Health Center, Boston, MA, June 1998
8. Medicine: Practice in the Latino Communty. HPREP Program, Weill Medical College of Cornell, New York, NY, March 1999
9. Cross-Cultural Primary Care: A Patient Based Curriculum. The Society of General Internal Medicine Annual Conference, San Francisco, CA, April 1999
10. Delivering Culturally Competent Treatment Services. Interamerican College of Physicians and Surgeons' Conference, New York, NY, April 1999
11. Physician Tools for Communication and Compliance: A Cross-Cultural Approach. Merck Medicaid Managed Care Advisory Board Meeting, Saybrook, CT, May 1999
12. Establishing the Link Between Cultural Competency and Racial and Ethnic Health Disparities. AHCPR's User Liaison Program: State Strategies for Promoting Cultural Competency in Health Systems: A Workshop for Senior State Health Officials, Charleston, SC, June 1999
13. Cross-Cultural Primary Care: A Patient-Based Approach. NY Presbyterian Hospital General Internal Medicine Conference, New York, NY, August 1999
14. Cross-Cultural Primary Care: A Patient-Based Approach. Gouverneur Hospital, New York, NY, September 1999
15. Establishing the Link Between Cultural Competency and Racial and Ethnic Health Disparities. Nebraska State Department Minority Health Conference, Omaha, NE, October 1999.
16. Cross-Cultural Primary Care: A Patient-Based Approach. NY Presbyterian Hospital Center for Special Studies, New York, NY, October 1999
17. Cross-Cultural Issues in Immigrant Access to Health.The New York Citywide Schweitzer Fellows Conference, New York, NY, October 1999
18. Defining Racial and Ethnic Disparities in Health. Keynote, NY Dietetic Association Meeting on Racial/Ethnic Disparities, New York, NY, November 1999
19. Eliminating Racial and Ethnic Disparities in Health: Federal Approaches and Collaborations. NY Presbyterian Hospital General Internal Medicine Conference, New York, NY, November 1999
20. Latino Leadership in Health Care. BLHO/Weill Medical College Health Policy Seminar Series, New York, NY, November 1999
21. Increasing Access through Provider Training: Cross-Cultural Medical Education. American Public Health Association Annual Meeting, Chicago, IL, November 1999
22. Addressing Racial and Ethnic Disparities through Provider Training: Cross-Cultural Medical Education. Office of Civil Rights Conference, New York, NY, November 1999
23. A New Approach to Cross-Cultural Care. Keynote, NY Hospital-Queens Multicultural Conference, New York, NY, November 1999
24. Cross-Cultural Primary Care: A Patient-Based Approach.Greater New York Hospital Association, New York, NY, December 1999
25. A New Approach to Cross Cultural-Care. Medical Grand Rounds, NY Downtown Hospital, New York, NY, December 1999

26. Establishing the Link Between Cultural Competency and Racial and Ethnic Health Disparities. Rogers Health Policy Colloquium, Weill Medical College of Cornell University, New York, NY, January 2000
27. Cross-Cultural Primary Care: A Patient-Based Approach. Medical Grand Rounds, Brown University, Providence, RI, February 2000
28. Cultural Competence in Managed Care: Challenges and Opportunities. National Hispanic Medical Association Annual Meeting, Washington, DC, February 2000
29. Establishing the Link Between Cultural Competency and Racial and Ethnic Health Disparities, Guest Lecturer, Creighton University, Omaha, NE, March 2000
30. Cross-Cultural Primary Care: A Patient-Based Approach, Guest Lecturer, UC-Davis Medical School, Sacramento, CA, March 2000
31. Hypertension in Multicultural and Minority Populations: Linking Communication to Compliance. Medicine Grand Rounds, Metropolitan Hospital, New York, NY, March 2000
32. Fundamentals of Cross-Cultural Medical Care. Medical Grand Rounds, North General Hospital, New York, NY, April 2000
33. Meeting Future Public Health Needs. AHRQ's User Liaison Program: Managed Care, Medicine, and Public Health—Building Collaborations that Work. Workshop for Senior Federal and State Health Officials, Jacksonville, FL, April 2000
34. Cross-Cultural Primary Care: A Patient-Based Approach. Keynote, Northshore Hospital Multicultural Conference, Great Neck, NY, April 2000
35. Eliminating Racial/Ethnic Disparities in Health: Exploring the Role of Academic Health Centers. The Society of General Internal Medicine Annual Conference, Boston, MA, May 2000
36. Cross-Cultural Primary Care: A Patient-Based Approach. Medical Grand Rounds, Emory University, Atlanta, GA, June 2000
37. Latino Health Policy: Key Challenges Ahead. Association of Hispanic Healthcare Executives, New York, NY, June 2000
38. Differences in Use of Hospital Procedures for Cerebrovascular Disease among Hispanics and Non-Hispanic Whites. DHHS HCFA Health Services Research Conference, Washington, DC, September 2000
39. Latino Access to Care: Addressing Challenges through a New Health Policy Framework. Spanish-American Medical Society Annual Meeting, Queens, NY, October 2000
40. Developing Cultural Competence Curriculum. Conference on Delivering Quality Care to Diverse Populations, Los Angeles, CA, October 2000
41. Commonwealth Fund Strategies: The Cultural Competence in Health Care Project. Conference on Delivering Quality Care to Diverse Populations, Los Angeles, CA, October 2000
42. Cross-Cultural Curricula: Current Approaches in Medical Education. Society for Education in Anesthesia Annual Conference, San Francisco, CA, October 2000
43. Delivering Quality Care to Diverse Populations: A Systems-Based Approach. LIU-C.W. Post Annual Ethics Conference, Long Island, NY, October 2000

44. Linking Communication to Compliance: A Cross-Cultural Perspective. New York State Department of Health HIV Coalition, New York, NY, October 2000
45. Increasing the Representation of Minorities in the Health Professions. Arthur Ashe Foundation-Association of NY Medical Schools, New York, NY, October 2000
46. Chronic Diseases in Communities of Color. Health Resources and Services Administration Conference, San Juan, PR, December, 2000
47. US Immigration and Immigrant Health: Trends, Challenges, and Policy Approaches. United Nations Association, Salt Lake, UT, February 2001
48. Cultural Competence in Health Care: Policy and Practice. National Hispanic Medical Association Annual Meeting, Washington, DC, March 2001
49. Delivering Quality Care to Diverse Populations: Workforce Challenges and Opportunities. AHRQ's User Liaison Program for Senior Federal and State and Federal Officials: Strategies for Eliminating Health Disparities, Tucson, AZ, April 2001
50. Definition and Measurement of Race/Ethnicity in Research. The Society of General Internal Medicine Annual Conference, San Diego, CA, May 2001
51. Teaching Racial/Ethnic Disparities to Residents. The Society of General Internal Medicine Annual Conference San Diego, CA, May 2001
52. Cultural Competence: Delivering Quality Long Term Care. New York Association for Housing and Services for the Aged, Albany, NY, May 2001
53. Teaching Cross-Cultural Primary Care: A View from the Field. The California Endowment Language Access Symposium, Oakland, CA, June 2001
54. Diversity in Healthcare: Expanding our Perspectives. Academy for Health Services Research and Health Policy Conference, Atlanta, GA, June 2001
55. Delivering Quality Care to Diverse Populations: Challenges and Opportunities. The California Endowment Board of Directors Meeting, Monterey, CA, July 2001
56. Discrimination, Prejudice, and Stereotyping: The Role of Race/Ethnicity, Culture and Class on Physician Decisionmaking. The New York Academy of Medicine New York, NY, October 2001
57. Cultural Competence in Long Term Care. NY Foundation for Long Term Care Cooperstown, NY, November 2001
58. The Notion of Cultural Competency. The California Endowment, Los Angeles, CA, January 2002
59. Meeting the Challenges of Diversity and Professionalism: Training for Cultural Competency The United Hospital Fund-The Soros Foundation, New York, NY February 2002
60. A Summary of IOM Report "Unequal Treatment". Testimony to Congress (Sponsored by the Congressional Black Caucus). April 2002
61. The IOM Report on Racial/Ethnic Disparities in Health Care: Findings, Recommendations, and Concrete Next Steps. The Society of General Internal Medicine Annual Conference, Atlanta, GA. May 2002

C. Report of Mentorship

1. Local Contributions

a. Undergraduate Education

Harvard Medical School (Coordinator)

2001	Harvard Summer Health Policy Internship (Hector Cariello, American International College)

Massachusetts General Hospital

2002	Summer Research Training Program (Gia Landry, HMS)

b. Medical School

Harvard Medical School

2001-	Hispanic Medical Student Mentorship Program (Eric Miranda, HMS; Fidencio Saldana, HMS '01)
2002-	Holmes Society Fellow
2002-	Preceptor for Primary Care Clerkship (Grace Lopez, HMS)

c. Graduate Medical Education

Massachusetts General Hospital

2001-	Department of Medicine Resident Preceptor (Marco Perez, MGH)

PART III

BIBLIOGRAPHY

A. Original Reports

1. Carrillo JE, Green AR, Betancourt JR. Cross-cultural primary care: a patient-based approach. Ann Intern Med. 1999:130:829-834.
2. Betancourt JR, Carrillo JE, Green AR. Hypertension in multicultural and minority populations: linking communication to compliance. Curr Hypertens Rep. 1999. 1:482-488.
3. Betancourt JR, Jacobs EA. Language barriers to informed consent and confidentiality: the impact on women's health. J Am Med Womens Assoc 2000; 50:294-5.
4. Betancourt JR, Green AR, Carrillo JE. The challenges of cross-cultural health care: perspectives on diversity, ethics, and the medical encounter. Bioethics Forum 2000;16:27-32
5. Green AR, Betancourt JR, Carrillo JE. The social history revisited: integrating social factors into cross-cultural medical education. Acad Med 2002;77:193-197.
6. Elixhauser A, Weinick R, Betancourt JR, Andrews R. Differences between Hispanics and non-Hispanic whites in use of hospital procedures for cerebrovascular disease. Ethn Dis 2002; 12:29-37.
7. Green AR, Carrillo JE, Betancourt JR. Why the disease-based model of medicine fails our patients. West J Med 2002;176:141-143.

B. Reviews. Commentaries. Chapters. and Educationally Relevant Publications

Commentaries:
Green AR, Betancourt JR, Carrillo JE. The relation between somatic symptoms and depression (letter). N Engl J Med. 2000; 342:658

Betancourt JR. Federal Efforts to Eliminate Disparities: A Call to Arms for Academic Generalists. Society for General Internal Medicine Forum, January 2001

Betancourt JR. IOM Tackles Health Disparities. Society for General Internal Medicine Forum, March 2002

Invited Editorials:
Betancourt JR, King RK. Diversity in healthcare: expanding our perspectives. Arch Pediatr Adolesc Med. 2000; 154:871-2.

Article Consultations:
Balk SJ, Betancourt JR, Chicoye LS, et al. Eliminating disparities in asthma management.Article consultants, Patient Care 2000; 34(9):160-187.

Betancourt JR, Johnson M, Valadez A. Reducing the burden of diabetes and CVD. Article consultants, Patient Care 2000; 34(9):28-48.

Chapters:
Carrillo JE, Trevino F, Betancourt JR, Coustasse AR. Latino Access to Health Care: The Role of Insurance, Medicaid Managed Care, and Institutional Barriers. In: Health Issues in the Latino Community. Marilyn Aguirre-Molina, Carlos Molina, Ruth Zambrana, Eds. Josey-Bass: New York. 2001 (Chapter 3).

Betancourt JR, Lavizzo-Mourey R. Cross-Cultural Education in the Health Professions. In: Institute of Medicine Committee on Understanding and Eliminating Racial/Ethnic Disparities. Institute of Medicine Press: Washington, D.C.; (pending publication).

Green AR, Betancourt JR, Carrillo JE. Providing Culturally Competent Care in the Hospital Setting. In: A Guide to Hospitals and Inpatient Care. Eugenia Siegler, Saeid Mirafzali, Janice Foust, Eds. Springer: New York. (pending publication)

Commissioned Papers:
Betancourt JR. The State of Cross-Cultural Medical Education.
Physicians for Human Rights Blue Ribbon on Racial/Ethnic Disparities in Health, June 2001

Betancourt JR. Health Outcome Measures for Evaluating Success in Teaching Cultural Competence. Association of American Medical Colleges, July 2001

Reports:

Betancourt, JR. Analysis of the Puerto Rican Health Care Reform. US Public Health Service/Department of Health of Puerto Rico, San Juan, PR, March 1997

Betancourt JR. Latino Diabetes Program Structural Assessment: New England. Dept. of Health and Human Services-Public Health Service: Region I Boston, MA January 1998-May 1998

Betancourt JR, Carrillo JE. Environmental Scan: Latino Access to Primary and Preventive Care. Secondary Barriers to Care: Organizational and Structural Factors. Commissioned Report to the Robert Wood Johnson Foundation, November 2000.

Green AR, Betancourt JR. Latino Environmental Scan: Latino Access to Primary and Preventive Care. Tertiary Barriers to Care: The Provider-Patient Encounter. Commissioned Report to the Robert Wood Johnson Foundation, November 2000.

Abstracts

Scheffler J, Betancourt JR, et. al. Interaction of Ro 82-0860 with Gap 334. The Hoffman LaRoche Research Department, Nutley, NJ, August 1991

Betancourt, Joseph R. The Key to Medical School Recruitment: What Shapes the Young Hispanic Mind. Eighth and Eleventh Hispanic Medical Congress, San Juan, PR, September 1993, 1996

Betancourt JR, Carrillo JE, Callahan ME. Observations from Latinos at an Outpatient Practice: Implications for Medicaid Managed Care. Cornell-Empire Blue Cross/Blue Shield Managed Care Conference, New York, NY, April 1997

Betancourt JR, Carrillo JE, Callahan ME. Observations from Latinos at an Outpatient Practice: Implications for Medicaid Managed Care. The Association for Health Services Research Annual Conference, Washington, DC, June 1998

Carrillo JE, Betancourt JR, Green AR. Limitations of Disease Management Programs in Voluntary Enrollment Medicaid Managed Care. The Association for Health Services Research Annual Conference, Chicago, IL, June 1999

Green AR, Betancourt JR Carrillo JE. Innovations in Cross-Cultural Education. The Society of General Internal Medicine Annual Conference, Boston, MA, May 2000

Elixhauser A, Weinick R, Betancourt JR, Andrews R. Differences in Use of Hospital Procedures for Cerebrovascular Disease among Hispanics and Non-Hispanic Whites. The American Public Health Association Annual Conference, Boston, MA, November 2000; The Association for Health Services Research Annual Conference Los Angeles, CA, June 2000

Betancourt JR, Nielsen R, Castro D. Public Health Modeling: Designing a Student Health Practice. The American Public Health Association Annual Conference Boston, MA, November 2000

Betancourt JR, Green AR, Harris J, Charles C, Meyer BR, Carrillo JE. Cultural and Linguistic Barriers in an Urban Academic Outpatient Practice: Observations from Doctors in Training. The Academy for Health Services Research and Health Policy Conf Atlanta, GA June 2000; The Society of General Internal Medicine Annual Conference San Diego, CA, May 2001

PART IV

ADDITIONAL INFORMATION

A. Certifications

Basic and Advanced Life Support, October 1993
Licensed Physician, State of New York, September 1995
Flexible Sigmoidoscopy, December 1996
Diplomate, American Board of Internal Medicine, October 1997
Licensed Physician, State of Massachusetts, March 2001

B. Media Coverage

"Latino Bone Marrow Drive" Interview on Latino Bone Marrow Drive in New York WNBC-TV News 4 New York, September 1994

"Los Hispanos Tambien Pueden Ser Medicos" Interview in TEMAS Magazine, March 1997

"Hablemos de Salud" Spanish Call-in show on Latino health issues WNVT-TV, Arlington VA, March 1999

"The Patient's Bill of Rights" Interview, "Edicion Seminaria" Spanish News Show Radio Bilingue International Radio, July 1999

"HMO Reform and the Patient's Bill of Rights" Interview, "Linea Abierta" Spanish News Show, Radio Bilingue International Radio, September 1999

"Cross-Cultural Medical Education" Interview, "Closing the Gap" Website www.closing-the-gap.com January 2000

"The Health Care Fairness Act of 1999" Interview, "Closing the Gap" Website www.closing-the-gap.com January 2000

"Hispanic Access to Health Insurance" Interview, "Linea Abierta" Spanish News Show Radio Bilingue International Radio, April 2000

"HIV/AIDS in Latino Adolescents" Spanish Call-in Show on Latino Health Issues WBNN-TV, Bronx NY, May 2000

"HIV/AIDS in Latinas" Spanish Call-in Show on Latino Health Issues WBNN-TV, Bronx NY, May 2000

"Asthma and Latinos" Spanish News Show "Aqui y Ahora" Univision Network (International TV), July 2000

"Doctors Can Help Close Gap in Disparities" Press Release, American News Service www.americannews.com July 2000

"Health Care: The 2000 Presidential Election" Interview, "Linea Abierta" Spanish News Show, Radio Bilingue International Radio, November 2000

"Immigrant Health and Globalization" Interview, Public Affairs Hour, National Public Radio, February 2001

"Barriers to Health Insurance for Hispanics" Interview, "Linea Abierta" Spanish News Show, Radio Bilingue International Radio, July 2001

"Racial Gap Leads to Health Disparities" Interview, The Nation, The Boston Globe Newspaper, August 2001

"HIV/AIDS in Latinos: Communication and Adherence" Interview, "Consultorio Communitario" Spanish Community Health Show, WACA-1400AM, Washington, DC. November 2001

"Addressing Diversity in the Health Care Setting to Achieve Quality", Interview, The Quality Letter for Healthcare Leaders, December 2001

"Report Finds Minorities get Poorer Health Care", Interview, Cable News Network (CNN), March 2002

"Health Care Divide", Interview, Lehrer Newshour, Public Broadcasting System, March 2002

"Racial Inequalities in Health Care", Interview, Talk of the Nation, National Public Radio, March 2002

"Racial Inequalities in Health Care: Are Doctors to Blame?", Interview, On Point, National Public Radio, March 2002

"Fed Report Cites 'Prejudice' in White, Minority Health Care Gap", Interview, Boston Herald, March 2002

“Closing a Health Care Divide”, Interview, New York Newsday, March 2002

“Study Alleges Bias in Medical Services for Minorities”, Interview, Los Angeles Times, March 2002

“IOM Study on Health Disparities”, Spanish Interview, Telemundo, March 2002

“Medical Help Lost in Translation”, Interview, Orlando Sentinel, April 2002

C. Languages

Spanish, fluent spoken and written

Confronting Inequality: Disparities in the Provision of Health Care Among Racial, Ethnic and Geographic Populations

A Special Oversight Hearing of the Joint Committee on Health Care
June 4, 2002
State House, Boston

Testimony of

Gisele Thornhill, MD, MPH
Massachusetts League of Community Health Centers

Introduction

My name is Dr. Gisele Thornhill and I am the Director of Clinical Health Affairs for the Massachusetts League of Community Health Centers, the membership association of the 49 community health centers across the state. I am a practicing physician and currently provide primary health care services to a predominantly Latino patient population through the Martha Eliot Health Center in Jamaica Plain, Massachusetts which I have been doing for the past five years.

On behalf of the Massachusetts League of Community Health Centers I would like to applaud Senator Moore, Representative Stanley, and the members of the Joint Committee on Health Care for holding a hearing on the critical issue of health disparities and thank you for the opportunity to provide testimony on this topic.

Background:

In September of 1984, I attended the Fourteenth Legislative Weekend of the Congressional Black Caucus Health Braintrust in Washington, DC. During this time a panel discussion was held titled "Bridging the Health Status Gap: A Federal Response". Present on the panel were the Honorable Edward Brandt, Assistant Secretary of the U.S. Department of Health and Human Services and Dr. Thomas Malone, Deputy Director of the National Institutes of Health, a black physician who was appointed by the Secretary of Health Margaret Heckler to chair a new Task Force on Black and Minority Health. Mr. Brandt reported the administration had instituted a number of programs to address the disparate health status of blacks but did not elaborate on the nature, efficacy or outcomes of these programs.

At the time, Dr. Thomas Malone had been assigned the task of setting up subcommittees to research individual categories of disparities in health status between whites and blacks namely, low birth weight, suicide/homicide rates, incidences of cancer, diabetes, cardiovascular disease and infant mortality. At the conclusion of their research the subcommittees were to provide appropriate recommendations to address these disparities. The irony was that that I had spent the better part of the previous day listening to well-credentialed individuals citing statistics and conclusions regarding disparities that had been heard many times before and I cynically anticipated that I would hear them again. Nevertheless, the initial Task Force on Black and Minority Health drew mainstream attention to the issue of disparities in health status Among certain racial groups.

Since 1985 there has been progress. The issues and discourse related to health disparities has moved beyond a primary focus on the black population to include Hispanics, Asian and Pacific Islanders, Native Americans, and other categories. We have also begun to look at disparities related to gender, age, and sexual orientation. Additionally, the U.S. Department of Health and Human Services launched the Healthy People 2000 initiative followed by Healthy People 2010, designed to achieve two overarching goals: 1) to increase the quality and years of healthy life, and 2) to eliminate health disparities by the first decade of the 21st century.

As a nation we have managed to narrow the health gaps in some areas, but they have increased in others. While overall age-adjusted death rates from heart disease, stroke and cancer have declined, the disparities in average life expectancy continue to exist, differentials in disease burden are well known and achieving equity in the distribution of the positive advances in treating diseases such as HIV/AIDS and the improvements in infant mortality rates between and among the different racial and ethnic groups still challenge us.

The first sentences of the abstract of the Institute of Medicine's pre-published report titled *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care* astutely and concisely summarize the past and current circumstances that result in health disparities in our nation.

> "Racial and ethnic minorities tend to receive a lower quality of healthcare than non-minorities, even when access-related factors, such as patients' insurance status and income, are controlled. The sources of these disparities are complex, are rooted in historic and contemporary inequities, and involve many participants at several levels, including health systems, their administrative and bureaucratic processes, utilization managers, healthcare professionals, and patients."

To establish effective solutions to the health disparities problem, any intervention and or action taken to foster health equity must ultimately translate into positive change that impacts at the level of the health provider and the individual patients that comprise the populations that bear the burden of the disparities in health. They must also translate into broad changes that impact the health delivery system in a sustainable and continuous fashion. Solutions must be comprehensive and must be directed at the multiple factors that contribute to the racial and ethnic disparities in health care. For the present discussion I would suggest that strategies for the elimination of health disparities begin with a focus in the following areas:

- The overall historical and evolutionary context of our nation as it relates to racial bias and its effect within the health care delivery system.
- The models of health care and the health workforce capacity
- The clinical encounter between patients and health providers and the interface with the health system as a whole.
- Structures that promote healthy living, healthy behavior and prevention.
- The fragmentation of efforts to decrease health disparities

Discussion

Addressing Racial Bias and Discrimination in Health Delivery

Finding 2-1 of the IOM report states racial and ethnic disparities in healthcare occur in the context of broader historic and contemporary social and economic inequality, and evidence of persistent racial and ethnic discrimination in many sectors of American life.

This is where we must begin, we need to accept and acknowledge the fact that racial discrimination exists and that this is not a matter of perception. Although the perceptions differ between those that are discriminated against and those who live without questioning whether they experience racial bias, reality and scientific evidence support the assertion that discrimination based on race and ethnicity exists. We need to talk openly about it and actively address the disparity in perception. We need to understand how racial bias and discrimination play out in the health care system and in the decisions made by providers and patients that affect health. Moreover, we need to plan for the fact that racial discrimination exists in the health system so that the racism, however unintended, can be counteracted.

I would like to call your attention to one of the articles provided to the Committee titled *Institutional Racism and the Medical/Health Complex: A Conceptual Analysis* by Gary King, PhD for the Committee's review. It provides a theoretical framework for discussion and for understanding how race and ethnicity result in structural impediments that influence not only the delivery of health care, but also the perceptions of the system of care and its potential utilization.[1]

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[1] King, Gary Institutional Racism and the Medical/Health Complex: A conceptual Analysis, Ethnicity & Disease 1996, Volume 6: 30 - 46

Discrimination in health care is not new. It is as old as the foundation of the United States though not well documented until done so by black physicians through the National Medical Association's health professional journals in 1909. Since that time there have been numerous articles, mostly concerned with the African American population until the past few decades. To gain insight into how race and ethnicity play out in the health care system and affects providers as well as patients I urge members of the Joint Committee on Health to take advantage of the recent availability of two books, *An American Health Dilemma: A Medical History of African Americans and the Problem of Race* (Volume 1*) An American Dilemma: Race, Medicine, and Health Care in the United States 1900 –2000* (Volume 2*)* written by Dr. W. Michael Byrd and Dr. Linda Clayton, two African American physicians who currently reside in The Boston area.. These volumes provide a comprehensive review of the origins, evolution, and perpetuation of racial and ethnic disparities in the United States from the beginning of our nation until now and provided much to the background of the Institute of Medicine Unequal Access report. These books have been well recognized and have were nominated for a Pulitzer Prize.

A Model of Care That Works

Since the mid 1960's, when the first urban community health center was founded at Columbia Point in Dorchester, community health centers (CHCs) have provided essential primary care services including preventive, dental, and mental health care. The history of CHCs is intimately tied to a movement in the United States to increase health care access and deal with issues of disparate health and equity. At the same time Medicaid and Medicare were being instituted to break down some of the financial barriers for the elderly and the poor and federal grants were being made to medical schools in an effort to increase enrollment. It was hoped that health centers would assume responsibility for creating a new kind of institution in the health care delivery system, serving defined communities and populations, and changing the emphasis from complex tertiary care to primary care and establishing new patterns of organization stressing multidisciplinary teams that included paraprofessionals recruited from the target communities.[2] With the advent of CHCs that provided new avenues of access for the poor and underserved health disparities dramatically decreased.

Today, in addition to community-based primary care, CHCs generally provide a broad array of assistance and enabling services such as case management, health education, nutrition counseling, transportation, translation and interpreter services and child care. Led by community-based boards of directors, health centers strive to meet the unique needs of their communities in linguistically and culturally competent ways. In Massachusetts, 49 community health centers currently provide health services at over 100 sites throughout the state. In 2001, these health centers provided nearly 3 million visits for over 600,000 people in need of medical, dental, outreach, and social services. Nationally, CHCs in the aggregate are the second largest providers of health care in the country.

CHCs emerged as a model of care that was structured from the very beginning to not only provide health care, but to provide it in a way to meet the needs of the most medically underserved and vulnerable populations, those at most risk of experiencing health disparities. Studies and data demonstrate the value of the CHC model in reducing emergency room use, decreasing hospitalizations, decreasing the incidence of low birth weights, improving chronic disease management, and excelling in providing preventive health interventions. Additionally, national studies indicate that every dollar invested in community health centers generate an average savings of three dollars to the overall health care system. Newer

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[2] Reynolds, David An Analysis of the Political and Economic Viability of Community health Centers: Implications for their Future, 2001: 4-5

studies are providing evidence that CHCs are successful in reducing and eliminating health access disparities by establishing themselves as their patient's usual and regular source of care.[3] Health centers have become part of the fabric of their communities providing health care access to all regardless of medical status, their ability to pay, or the patient's culture or ethnicity. Lessons learned through community health centers are transferable and can contribute to eliminating health disparities in other health delivery settings.

Despite the success, many health centers are struggling to provide services as they strive to meet the demand of the increasing number of uninsured and underinsured. They cannot afford to take advantage of the technological advances that can assist with practice management that would make it easier to deliver the high quality health care services and manage their patient care more efficiently and effectively. Given the populations that health centers serve and the success of the model of health care delivery it is important that health centers remain viable as a model of care, particularly as changes continue to take place in the medical marketplace and funding steams become more limited.

Health disparities are likely to widen should health centers succumb to the current fiscal and economic pressures evolving in the medical environment. Funding at the state level should be expanded to ensure the viability of health centers. Additionally, programs such as the state Medicaid program and the uncompensated care pool and other like programs, for which many CHC patients are eligible, must be structured to maximize the likelihood that the cost of their care is covered.

The Massachusetts League of Community Health Centers[4] and its 49 member CHCs stand ready to work with the legislature and the Joint Committee on Health Care and assist in whatever way we can to further efforts to eliminate racial and ethnic health disparities in Massachusetts.

Enhancing Health Workforce Capacity to Eliminate Health Disparities

The Kaiser Family Foundation recently reported on a national survey of physicians titled *Doctors on Disparities in Medical Care.* Similar to findings of other studies examining the perception of racial discrimination among different racial and ethnic groups in the general population, physicians of different race and ethnicity also tend to perceive disparities in the health care system very differently. African American physicians are more likely than white and Asian physicians to believe that the health care system at least "somewhat often" treats people unfairly based on various characteristics. The most striking differences in perception of the health care system were related to the characteristics of race and ethnicity.[5]

Efforts towards health disparity elimination are aided by having an adequate, diverse, culturally competent professional health workforce. As mentioned above, there is a disparity of perception among health providers relative to the influence of race and ethnicity and health outcomes. Providers need to be educated about health disparities and at the same time need to be introduced to the concepts and skills to achieve cultural competence. They also need to be given guidance and a framework for how to achieve cultural competence. This instruction should begin as early as possible in the training process of health professionals. Schools of nursing, medical schools, dental schools, allied health professional institutions

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[3] Politzer, Robert et al, Inequality in America: The Contribution of Health Centers in Reducing and Eliminating Disparities in Access to Care, Medical Care Research and Review, Vol. 58 No.2: 234-248

[4] See attachments to this written testimony for more information on the League and community health centers.

[5] The Kaiser Family Foundation, National Survey of Physicians Part I: Doctors on Disparities in Medical Care, March 2002.

and residency training programs should be required to incorporate curricula that address health disparities and cultural competence in addition to the traditional curricula.

The health professions workforce needs to reflect the diversity of the nation and the state. Patients need to see health professionals that look and talk like them and who may also have a shared culture with their patients because of the historical and social context of the health care system and how it has interfaced with the populations that experience health disparities. Policy makers need to consider how to influence the supply of health providers to meet the needs of these populations in terms of access to primary care providers and medical specialists, particularly at the community level. Studies have shown that patients fair better when seeing a provider of the same racial or ethnic group and who also can provide a continuous source of care. Patients are more trusting of their provider relationship and are more likely adhere to their health provider's medical advice and may have better health outcomes when this is the case. It is unlikely, however, that the state or the nation will be able to generate the diversity needed among health providers to meet the need of patients based upon a shared race/ethnicity or culture. Making it all the more important that all health providers be trained to provide services in a culturally competent way.

Equally important is the successful recruitment and retention of health personnel to health settings that serve a large proportion of racial and ethnic populations. These health settings tend to draw low-income patients, have limited resources for infrastructure and may be located in less desirable areas than other practice settings These circumstances make it more difficult to attract and retain high quality personnel. Massachusetts needs to do all it can to ensure a supply of well-qualified professional to care for those that experience disparities in health status. Funding for programs such as the Physician State Loan Repayment Program must continue and innovative ways of leveraging other dollars and incentives must be created not only for physicians, but also for other equally important disciplines of health professionals.

The Clinical Encounter and Patient Interfaces with the Health System

The historical structure of health delivery has been predicated on the pairing of an independent health professional, usually a physician, and an individual patient. Over the years there has been a shift from relying solely on the independent health professional as the sole decision-maker, directing and instructing a much less informed patient, to a partnering relationship with the patient and a collaboration that incorporates other non-physician health professionals working with the individual patient and others to achieve the best health of the patient. However, this shift in approach to patient care may be a false perception, at least of the contemporary the health professional. The balance of power relative to medical decision-making is on the provider's side by virtue of professional prestige, technical expertise, and the situational dependency of the patient. What does this mean for the clinical encounter of patients, particularly patients of color who are more likely to be less educated and less informed about their medical condition and options for treatment and management?

> "Patient-practitioner relationships are best viewed in the framework of social roles, of the attitudes and activities the two parties bring to the situation of care. This interaction of two or more persons, centering around the health needs of a single individual, is far from being a spontaneous happening. It is rather, a more or less well-rehearsed confrontation in which the key participants have learned to expect certain things and to act in certain ways....What is the implication of constructing health care as a social role relationship? It means, first, that this interaction between a helping agent and a person needing help is patterned and hence, shows predictable regularities..." [6]

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[6] Wilson, Robert, the Sociology of Health: An Introduction, Random House publishers, 1970: p13

To change the predictable pattern of health outcomes, patients and providers must be empowered to change. Besides educating health providers and the lay health professionals we also need to educate the public regarding the existence of health disparities, and what promotes health and how they can take personal responsibility for resolving this issue. Patients and communities need to be empowered with knowledge and health providers need to be called to task to provide the right care at the right time consistent with evidence-based medicine. Whatever structures need to be reinforced or put in place to make this happen must be put in place. Every opportunity that is available to interface with the public and provide health information in a culturally and linguistically appropriate fashion must be taken advantage of. We must be innovative and creative and move outside of the traditional boxes to make this happen. Providers and health systems of care must be monitored and held responsible for providing appropriate care regardless of the race or ethnicity or language of the patient.

Promoting Healthy Behaviors and Prevention

Prevention works. The old adage of " an ounce of prevention is worth a pound of cure" is true. Cardiovascular procedures and the lack of access for some groups would not be as much of an issue if cardiovascular disease did not exist. Unequal rates of organ transplantation would not be an issue if the medical conditions that put individuals at risk for diseased organs were prevented or diagnosed and treated early. We must ask ourselves have we done all we can with regard to prevention efforts among the populations at risk for disparate health outcomes? Can we do something to make it more likely that people will participate in healthier lifestyles? For example, could urban areas be redesigned to promote increased physical activity e.g. jogging, walking, and bicycle paths? Could incentives for employers be created to provide healthier lunchroom and vending machine foods or physical activity outlets for their employees?

Additionally, have public health prevention programs that have demonstrated success continued to be funded and expanded? Can we find ways to better bridge medicine and public health?
Can we find ways to sustain community programs that have demonstrated that they work at the community level?

Decreasing the Fragmentation of Efforts to Eliminate Health Disparities

There are a myriad number of organizations and agencies, public and private, and advocacy groups representing various constituencies all attempting to address the health disparities issue. All are working on one or a number of fronts to resolve the health disparity issues that they are passionate about. Each seeking financial and other supports, in many cases from the same funding entities, and advocating for their constituencies. The result of this is a diluted process that at best may favor incremental steps rather than substantial gains in the fight to eliminate health disparities.

In response to the plethora of fragmented efforts to address health disparities across the state of Massachusetts, in June of 2001 representatives from a group of agencies came together to discuss how to best address the growing problem of health disparities. The group calling itself Critical MASS for eliminating health disparities, has emerged to capture and enhance existing efforts through a coordinated state-wide plan designed to maximize traditional and non-traditional resources and ensure program development that cuts across all ages, racial and ethnic groups and health areas where health disparities lie. Agreeing upon a common mission statement, Critical MASS has developed goals and objectives to carry out its mission and a set of core operating principles (See attachment). The goals and objectives support and overlap many of the recommendations of the Institute of Medicine as outlined in its *Unequal Treatment* report.

The group's participants bring not only years of professional experience in the arena of public health, outreach and research, but also the racial and ethnic diversity that is sometimes lacking in many collaborative networks. While there are many efforts addressing health disparities for specific populations, Critical MASS plans to use a statewide, comprehensive and collaborative model to link existing programs and increase shared capacity. The Massachusetts League of Community Health Centers has recently formally endorsed Critical MASS and is a currently sends a representative to participate as a collaborative member. Collaborations like Critical MASS should be recognized as part of the armamentarium in the effort to eliminate health disparities. These types of collaborations should be encouraged and supported at a state level.

Finally, I challenge the Joint Committee on Health Care needs to remain vigilant, resolute, creative and innovative in its attempts to find solutions for the health disparities issue as a legislative body. I also invite the Committee to commit to sending a legislative aide or other appropriate representative of the committee to engage with members of Critical MASS as the Committee proceeds in its activities and attempts address the on the issue of racial and ethnic health disparities in the Commonwealth.

A summary of recommendations follows the end of this testimony, which I respectfully submit for the Committee's consideration.

Once again, I applaud the Chairs and the members of this committee on your efforts to address and give voice to the health disparity issue on a state level. I thank you for your contribution to strengthening my hope that significant change can and will be made in my lifetime.

Summary of Recommendations:

1. Acknowledge and address the issues of racial bias and discrimination and their historical and contemporary relationship racial and ethnic health disparities. Plan for the fact that racial discrimination exists in the health system so that racism, however unintended, can be counteracted.

2. Take steps to ensure the financial viability of the community health centers and the health center model of care, including continued and expanded state funding and the restructuring of programs like Medicaid and the uncompensated care pool, to maximize the likelihood that the cost of providing basic medical, dental, and preventive care to eligible patients are covered.

3. Require health disparities education be incorporated early in the curricula of medical, dental, nursing and other allied health profession schools related to the nature and causes of health disparities. Similarly, require cultural competency training.

4. Create opportunities to increase the health professional workforce, particularly with regard to racial and ethnic group representation, and expand funding for the Physician State Loan Repayment Program and like programs and provide other incentives for health professionals to practice and work in practice sites serving large numbers of racial and ethnic groups.

5. Create venues for informing the general public regarding the existence and extent of health disparities and provide health information to empower the lay public to take more control of their health care and to better partner with their health provider in making health decisions. This includes being able to identify providers of similar culture and race or ethnicity.

6. Monitor providers and health systems and hold them accountable and responsible for providing the appropriate care at the right time consistent with evidence-based principles.

7. Engage urban design experts to create opportunities for the public to engage in healthy lifestyles and behavior such as walking/jogging and bicycle paths and create incentives for businesses and employers that promotes healthy lifestyles and behaviors, such as nutritious food availability in vending machines and business based physical activity outlets for employees.

8. Fund public health prevention programs and community programs that demonstrate success and find ways to promote the bridging of medicine and public health.

9. Promote the collaboration of agencies and organizations, such as Critical MASS, to decrease fragmentation of the many efforts attempting to address health disparities.

10. The Joint Committee on Health Care should maintain eliminating health disparities as a continuous priority and agenda. The committee must remain vigilant, creative, and innovative as it attempts to resolve the issue of health disparities.

HOW ARE COMMUNITY HEALTH CENTERS COST-EFFECTIVE?

- National studies indicate that every dollar invested in community health centers provides an average savings of three dollars to the overall health care system.
- Comprehensive case management, 340b ("best price") pharmacy programs and aggressive chronic disease management are examples of health center preventive care models which help minimize ER visits and preventable hospitalizations among low-income patients.
- Based on a recent study by the health center-based HMO, Neighborhood Health Plan (NHP), patients served by community health centers had less hospital admissions, hospital days and emergency room visits than did NHP patients who received their health care from hospital-based primary care sites.

WHY ARE HEALTH CENTERS SO IMPORTANT TO COMMUNITY DEVELOPMENT?

- Community health centers provide a source of stable employment for local residents, generating direct economic output, household income and employment to neighborhood residents.
- In some cases, health centers have played a significant role in revitalizing business districts in which they are located and have been key players in efforts to strengthen all aspects of community.
- Health centers provide job training and career building for their community residents.

WHAT IS THE MASSACHUSETTS LEAGUE OF COMMUNITY HEALTH CENTERS?

- Established by clinicians, administrators and community members in 1972, the "League" is the membership association for the state's 49 community health centers
- Mission: to provide leadership to its membership in achieving their goals and to promote accessible, quality, community-responsive health care
- Founder and member of the health-center based HMO, Neighborhood Health Plan, an affiliate of Harvard Pilgrim Health Care
- Founder and corporate partner of the Community Health Center Capital Fund, established in 1994 to assist health centers in developing and funding capital projects

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WHAT ARE COMMUNITY HEALTH CENTERS?

- Non-profit community-based organizations serving 1 out of every 10 patients in the Commonwealth
- Offer comprehensive primary and preventive health care, including medical, dental, social and mental health services to anyone in need regardless of their medical status, ability to pay, culture or ethnicity
- Provide culturally sensitive care
- Address the specific health needs of their communities
- In 2001, 49 community health centers provided 3 million visits through 104 sites statewide

WHAT DO COMMUNITY HEALTH CENTERS DO?

- Provide access to primary health care for medically underserved patients
- Promote good health through prevention, education, outreach and social services
- Services community health centers provide or arrange for:

Pediatrics
Obstetrics
Dental Care
Dermatology
Elder Services
Home Care
Public Health Programs
Substance Abuse
Adult Medicine
Gynecology
Mental Health
Podiatry
Family Planning
Nutrition/WIC
School Based Services
Immunizations
Family Medicine
Laboratory
Social Services
Acupuncture
Hospitalization
Specialty Referrals
Pharmacy Services
Smoking Cessation & Prevention

WHOM DO COMMUNITY HEALTH CENTERS SERVE?

- Medicaid recipients
- Low-income uninsured and underinsured
- High-risk populations
- Elderly
- Any individual in need of primary health care

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Critical MASS *for eliminating health disparities*

This working document of the mission, goals and objectives of Critical MASS has been recommended by the governance committee and ratified by the current membership with the agreement that they be reviewed annually and amended if needed. March 2002

Mission:
Critical MASS seeks to be a catalyst for the mobilization of a sustainable, statewide effort that accelerates the elimination of racial and ethnic health disparities.

Goals and Objectives:

1. To build a statewide multicultural network to advance the elimination of racial and ethnic health disparities.

   Objective 1.1: Identify stakeholders committed to eliminating health disparities.

   Objective 1.2: Identify partners whose interests are aligned with Critical MASS' mission.

   Objective 1.3: Create forums to bring stakeholders and partners together to plan, develop and implement strategies to eliminate health disparities.

2. To promote and improve the health and well being of racial, ethnic and immigrant and refugee populations.

   Objective 2.1: Identify existing policies that focus on eliminating health disparities and efforts in both the public and private sectors that support the elimination of health disparities

   Objective 2.2: Inventory current resources, best practices and identify gaps in policies, research and measures of health outcome.

   Objective 2.3: Develop a 5-year statewide plan to address the primary gaps identified above and recommend policies to close gaps in health outcome by race and ethnicity.

3. To coordinate Critical MASS with federal, regional, state, and local efforts to eliminate health disparities.

   Objective 3.1: Collect and disseminate information on activities across the state related to health disparities.

Objective 3.2: Create linkages to regional activities including the New England Regional Minority Health Committee.

4. To identify, create, or encourage the development of mechanisms to track progress on eliminating racial and ethnic health disparities.

   Objective 4.1: Define key indicators to track progress on eliminating racial and ethnic health disparities.

   Objective 4.2: Evaluate progress regularly based upon key indicators.

   Objective 4.3: Identify public and private databases that quantify health outcomes as a way to track progress.

5. To promote, improve and increase the capacity of researchers and communities to develop and conduct community participatory research which includes racial, ethnic, refugee, and immigrant perspectives in the design and implementation.

   Objective 5.1: Identify criteria for conducting inclusive research and collaborate with researchers to disseminate.

   Objective 5.2: Identify criteria for conducting community participatory research.

   Objective 5.3: Collaborate with community-based partners to educate communities about the full range and benefits of research activities.

   Objective 5.4: Identify and advocate for the adoption of policies to support community participatory research, and promote the development of researchers that represent the study populations.

Core Operating Principles:

1. A body of evidence exits that identifies a relationship between race, ethnicity, language, national origin, and health status. The network seeks to foster the development of systems and mechanisms to maximize health status for all individuals and their respective communities.

2. Shared understanding about the social determinants of health is critical to eliminating health disparities. By encouraging research that is inclusive of all populations, the network seeks to identify variables that contribute to the variances in health outcomes in Massachusetts.

3. Identification of key variables that lead to poor health outcomes requires that quality data be collected consistently across agencies, providers and institutions. The network promotes the development of such quality data sets and advocates for the reporting of data that track progress on improvements of the health status of racial and ethnic communities.

4. Stakeholders are individuals and organizations committed to health equity. The network seeks to involve all stakeholders including: public and community health educators, care and service providers participating in the work of eliminating health disparities

5. Communities that experience disparate health outcomes are critical partners in problem solving and program development that improve health and well-being. The network seeks to involve community members as active participants.

MASSACHUSETTS LEAGUE of COMMUNITY HEALTH CENTERS

100 Boylston Street, Suite 700, Boston, MA 02116 • (617) 426-2225 • Fax (617) 426-0097 • (800) 475-8455

David Martin
Chief of Staff
Office of Senator Richard T. Moore
Room 312-D State House
Boston, MA 02133

Dear Mr. Martin:

Attached please find articles and reference materials for the briefing package for members of the Joint Committee on Health Care. I hope these will reach you in time to be included with other contents of the committee's briefing package. If you are not able to include them I will include them as part of my written testimony and provide them on the date of the hearing. Should you have any questions do not hesitate to contact me.

Yours truly,

Gisele Thornhill,

Gisele Thornhill, MD, MPH

A practice we take pride in

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- Established by clinicians, administrators and community members in 1972, the "League" is the membership association for the state's 49 community health centers
- Mission: to provide leadership to its membership in achieving their goals and to promote accessible, quality, community-responsive health care
- Founder and member of the health-center based HMO, Neighborhood Health Plan, an affiliate of Harvard Pilgrim Health Care
- Founder and corporate partner of the Community Health Center Capital Fund, established in 1994 to assist health centers in developing and funding capital projects

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Inequality in America: The Contribution of Health Centers in Reducing and Eliminating Disparities in Access to Care

Robert M. Politzer
Jean Yoon
Bureau of Primary Health Care,
Health Resources and Services Administration,
Department of Health and Human Services
Leiyu Shi
Johns Hopkins School of Hygiene and Public Health
Ronda G. Hughes
Jerrilynn Regan
Marilyn H. Gaston
Bureau of Primary Health Care,
Health Resources and Services Administration,
Department of Health and Human Services

Reducing and eliminating health status disparities by providing access to appropriate health care is a goal of the nation's health care delivery system. This article reviews the literature that demonstrates a relationship between access to appropriate health care and reductions in health status disparities. Using comprehensive site-level data, patient surveys, and medical record reviews, the authors present an evaluation of the ability of health centers to provide such access. Access to a regular and usual source of care alone can mitigate health status disparities. The safety net health center network has reduced racial/ethnic, income, and insurance status disparities in access to primary care and important preventive screening procedures. In addition, the network has reduced low birth weight disparities for African American infants. Evidence suggests that health centers are successful in reducing and eliminating health access disparities by establishing themselves as their patients' usual and regular source of care. This relationship portends well for reducing and eliminating health status disparities.

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Persistent and widening health care access and health status disparitie (Center for Disease Control 1999) are particularly disturbing as evidenc emerges that links access to a usual and regular source of primary care wit improvements in health status, regardless of income (Shi and Starfield 2001) It has been argued that health care access can contribute only marginally t reducing or eliminating these disparities when facing formidable oppositio from lack of education, poverty, and poor social environment (Williams 1999 Wilkinson 1997; Kennedy, Kawachi, and Prothrow-Stith 1996). Evidence indicates that access to primary care alone can mitigate health status disparitie (Shi and Starfield 2001).

Internationally, there is concordance between the strength of a nation's primary care delivery system and its health status indicators (Starfield 1998). I studies within the United States, primary care was identified as the most significant medical care variable associated with better health status (Shi 1992, Farmer, Stokes, and Fisher 1991). One study demonstrated that primary care exerted a strong and significant influence on life expectancy and total mortality even after controlling for the adverse impact of income inequality (Shi et al. 1999). This study was replicated for U.S. metropolitan areas (Shi and Starfield 2001) and for several points in time (Shi and Starfield 2001) with similar results.

Other researchers have demonstrated the relationship between the performance of essential primary care functions and improved health status (Rosenblatt et al. 1998; Bunker, Frazier, and Mosteller 1994; Weiner and Starfield 1983). Studies have found that populations in geographic areas with higher family/general physician-to-population ratios had lower rates of avoidable hospitalization for Ambulatory Care Sensitive Conditions (ACSCs; Parchman and Culler 1994), and men appearing at emergency rooms with complications of hypertension were less likely to have a source of primary care than those without complications (Shea et al. 1992). Controlling for demographics and diagnoses, one study found that patients with a primary care physician as their personal physician had lower mortality than those with a specialist as their personal physician (Franks and Fiscella 1998). Finally, a recent study captured the domains of primary care (i.e., continuity, accessibility) and determined that quality primary care attenuates the adverse impact of income inequality on health (Shi and Starfield 2000).

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This evidence demonstrates that primary care services have the potential to mitigate the negative effects of income inequality on health status. However, this source of care must be regular and usual, user-friendly, and engender the trust of its patients. Services must be integrated and accessible, and delivered by clinicians who are accountable for addressing a large majority of personal health care needs and who develop and sustain effective provider-patient relationships in the context of family and community (Institute of Medicine 1996).

Poor, uninsured people from racial/ethnic minority groups seek care, if at all, from a variety of providers known as the nation's safety net. An appreciable percentage of such vulnerable people do seek care at the offices of private physicians. However, core safety net providers (for the most part) are hospital emergency rooms, outpatient departments, and health centers located in communities (Institute of Medicine 2000).

Health centers have a history that dates back to the mid-1960s (Lefkowitz and Todd 1999). Today's health centers provide comprehensive preventive and primary health care services to people living in federally designated rural and inner-city underserved areas at low or no cost to patients. In addition to conventional community-based primary care and preventive services, health centers generally provide a broad spectrum of assistance and enabling services such as case management, health education, nutrition counseling, transportation, translation, child care, and child parenting classes. Health centers coordinate with other community services and are governed by boards whose membership in the majority are health center patients. This national network of 700 centers serves nearly 10 million poor, uninsured Americans from racial/ethnic minority groups at more than 3,000 sites, including community, migrant, school-based, public housing, and health care for the homeless sites in all 50 states and territories. Approximately half of the health center patients are rural dwellers. Health centers receive more than one third of their revenue from Medicaid reimbursement, with additional smaller percentages from a variety of sources including Medicare, self-pay, and other public and private coverage. Contributing about 26 percent of their annual revenue, the Department of Health and Human Services' (DHHS) Health Resources and Services Administration's (HRSA) Bureau of Primary Health Care (BPHC) is the custodian of federal support for health centers. Health centers work to reduce and eliminate access barriers to become their patients' usual and regular source of care (Dievler and Giovannini 1998).

NEW CONTRIBUTION

This article synthesizes results from the most recent literature in an attemp to establish the link between access to primary care and reductions in health status disparities. It presents the most up-to-date data on the performance and effectiveness of federally funded health centers in providing such access to primary care for vulnerable populations.

DATA COLLECTION METHOD

The BPHC has established a three-stage data collection activity to assess the effectiveness of health centers. At Stage 1, the Uniform Data System (UDS) collects a variety of financial, socioeconomic, demographic, and utilization information for every health center that receives federal support. Second, in 1995 a survey was launched of health center patients who had received care from a health center the previous year using an instrument comparable to the Center for Disease Control and Prevention's (CDC) National Health Interview Survey (NHIS). By using a similar tool and method, peer (i.e., adjusted for age, race, and socioeconomic status) comparison groups were created from the NHIS data. NHIS survey respondents were included only if they had at least one medical encounter with a health care professional. The health centers survey included patient demographics, insurance coverage, self-perceived health status, access to care, quality of care, patient satisfaction, activities of daily living, receipt of preventive services, and treatment of chronic conditions (for details on methodology, see Regan, Lefkowitz, and Gaston 1999). Finally, intensive studies were conducted of health center medical records and other databases (such as the Health Care Financing Administration's State Medicaid Research Files) to compare outcomes of health center patients with similar patients who obtained care from other sources.

RESULTS

HEALTH CENTER PATIENTS

An estimated 43 million people (1 in 6 Americans) live in federally designated underserved areas and lack access to a private primary care provider (Lefkowitz and Todd 1999). In 1998, 8.7 million people, one fifth of the 43

nillion, were served by health centers. Generating more than 35 million ncounters, health center patients are more likely to be uninsured, poor, and rom racial/ethnic minority groups (BPHC 1998), individuals with significant ealth care needs who traditionally face substantial barriers to care (Fiscella t al. 2000). The vast majority of health center patients are people from acial/ethnic minority groups (see Table 1). Nearly two thirds are at or below he poverty level, and 20 percent are between 100 percent and 200 percent of overty (see Table 1). More than 40 percent of health center patients are uninsured (see Table 1). In fact, in two of five health centers, the majority of patients are uninsured (BPHC 1998). The number of uninsured patients in health centers has increased by nearly 60 percent since 1990, from 2.2 million to more than 3.5 million in 1998, representing about 8 percent of the nation's 44.3 million uninsured (BPHC 1999; U.S. Census Bureau 1999). Caseloads of private physicians in the primary care specialties include 10 percent uninsured, and clinics in hospital outpatient departments include 12 percent uninsured (Lefkowitz and Todd 1999). In addition, about 33 percent of health center patients are Medicaid beneficiaries (BPHC 1998), representing about 9 percent of the nation's 33 million Medicaid recipients (Lefkowitz and Todd 1999), while nationally Medicaid beneficiaries represent 10 percent of patients that seek care.

About 3.5 million (40 percent) of the health center patients are children, and 1.2 million or about one third are uninsured (BPHC 1998). Nearly 25 percent of the nation's 3.4 million poor, uninsured children seek and receive care at health centers (Lewis-Idema et al., Health Centers, 1999).

A greater percentage of health center patients in all age groups reported having fair or poor health status than in the U.S. population. While almost half of the health center patients were aged 45 to 74 years and more than half of those over the age of 74 reported having fair or poor health status, one third of the U.S. population ages 45 and older reported having fair or poor health status (BPHC 1995). Among those aged 25 to 44 years, 25 percent of health center patients had some activity limitation compared with 11 percent in the nation; for those aged 45 to 64 years, 48 percent had some activity limitation compared with 23 percent in the nation.

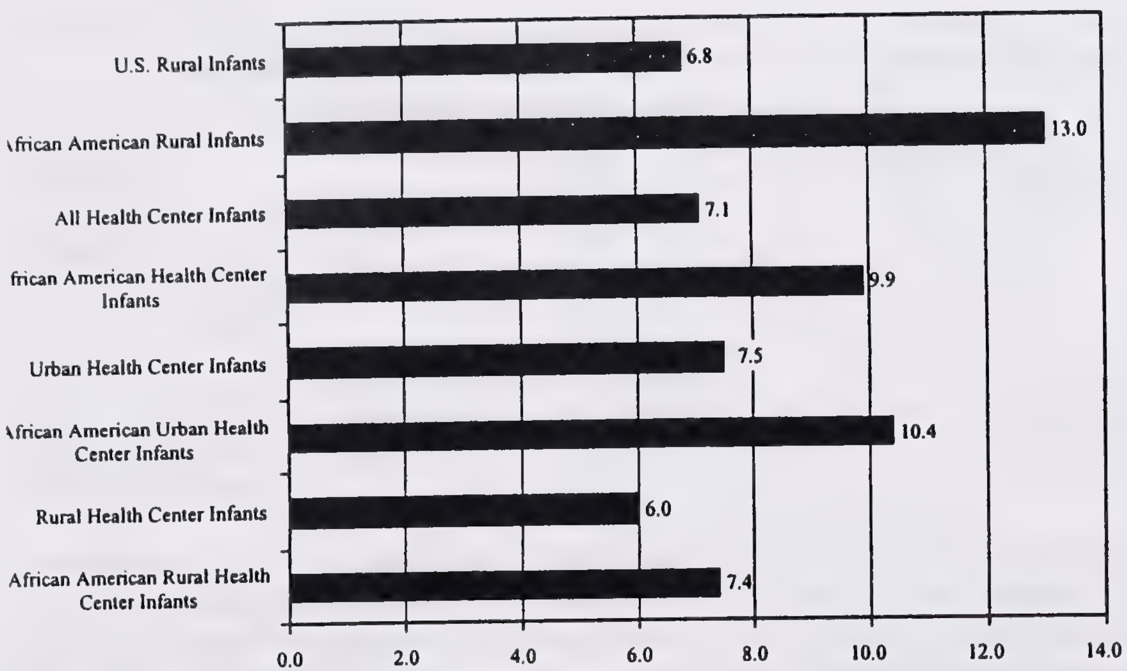
Nearly 2 million patient encounters in health centers are for hypertension, followed by more than 1.5 million for alcohol, drug dependence, or other mental disorder, and 1.4 million for diabetes (BPHC 1998). Overall, 36 percent of adult patients have been diagnosed with hypertension, compared with 27 percent for low-income U.S. adults. Half of middle-aged health center patients are hypertensive, significantly higher than the 34 percent for low-income middle-aged adults in the general population. While it is established that African Americans have the highest rates of hypertension in the nation, African American health center patients have even higher rates; nearly half have hypertension, compared with 35 percent for low-income, adult African Americans (Mathematica Policy Research 1998b). Also, the prevalence o diabetes is higher among health center patients. This finding holds regardless of racial/ethnic group, income level, age, gender, or even among the obese Even after controlling for risk factors such as obesity, race/ethnicity, and age health center patients are significantly more likely to have the diseas (Mathematica Policy Research 1998a).

TABLE 1 Distribution of Health Center Patients by Race/Ethnicity, Income, and Insurance

	n	%
Race/ethnicity		
White	3,117,129	36
Hispanic	2,943,955	34
African American	2,251,259	26
Asian/other	346,347	4
Total	8,658,690	100
Income		
Below poverty	5,714,735	66
100% to 200% poverty	1,731,738	20
Below 200% poverty	1,212,217	14
Total	8,658,690	100
Type of insurance		
Uninsured	3,550,063	41
Medicaid	2,857,368	33
Medicare	606,108	7
Other/private	1,645,151	19
Total	8,658,690	100

Source: Adapted from the Bureau of Primary Health Care (1998).
Note: Income is defined according to the federal poverty guidelines. Below 200 percent poverty is $33,400 for a family of four in 1999. Unknown were distributed as known.

About 7.1 percent of births to health center women are at or below 2,50 grams. This figure is comparable to the nation's, but health center women ar more likely to be teenagers and from racial/ethnic minority groups wit higher rates than the national average. African American women who us health centers give birth to low birth weight infants at a rate of 9.9 percent, i contrast to their national rate of 13.0 percent. Compared with national figures health center rates represent a 50 percent reduction in this disparity.



IGURE 1 Low Birth Weight among Rural, Urban, and Health Center Infants
ource: Adapted from the National Center for Health Statistics (1991) and the Bureau of Primary ealth Care (1998).

Rural health center infants have made even greater strides at eliminating this racial/ethnic disparity: African American infants from rural health centers had a low birth weight rate of 7.4 percent, representing a 77 percent reduction in the disparity between African American and all rural infants. Urban health center infants have demonstrated a reduction in racial disparity, but not to the extent as in rural health centers (see Figure 1).

ACCESS TO CARE AT HEALTH CENTERS

As previously noted, poor people from racial/ethnic minority groups face substantial barriers to health care (such as lack of insurance) and subsequently experience greater disparities in health status and health outcomes. Nationally, the majority of uninsured (55 percent) report that they delayed seeking care because of costs; 30 percent did not get medical care that they felt they needed, and 24 percent did not fill prescriptions (Hoffman 1998). A survey of health center patients found that these measures of unmet needs for those without insurance were significantly lower; health center uninsured patients reported rates that were about half the rates of the nation's uninsured

(25 percent, 16 percent, and 12 percent, respectively) (BPHC, 1995). While 75 percent of the nation's uninsured reported having a usual source of care, 99 percent of health center uninsured reported having a usual source of care (Mathematica Policy Research 1999).

A study comparing pediatric visits to health centers with such visits to hospital-based primary care clinics and generalist office-based practices revealed that a greater percentage of health center visits were made by known patients returning for a new problem (odds ratios: 1.77 for health centers, 1.0 for offices, and 0.70 for clinics). Hospital-based clinics and generalist office-based practices, on the other hand, saw a greater percentage of known patients for old problems (Forrest and Whelan 2000; Whelan and Forrest 1999). Other researchers have demonstrated that the visit category "known patient for new problem" can be used as a proxy for continuity of care (Starfield 1998).

PREVENTION/SCREENING

Health center uninsured adults are more likely to receive counseling on lifestyle issues than uninsured adults who seek care elsewhere. Health center uninsured adults are more likely to be counseled about diet and eating habits (54 percent vs. 43 percent), physical activity (57 percent vs. 48.5 percent), smoking (75.4 percent vs. 63.9 percent), drinking (67.8 percent vs. 52.3 percent), drug use (55.2 percent vs. 38.7 percent), and sexually transmitted diseases (53.7 percent vs. 36.2 percent) than U.S. uninsured adults. However, in most cases the health center rate has not met the Healthy People 2000 goal, except for physical activity and tobacco use (Mathematica Policy Research 1999).

Pap smears, mammograms, and clinical breast examinations can detect disease in its early stages, significantly reducing morbidity and mortality. Even though the long-awaited decline in U.S. breast cancer mortality has arrived, the disparity between African American and white women persists (Chevarley and White 1997). One of the factors contributing to higher mortality for African American women is their higher likelihood of later stage diagnosis. Nationally, mammography rates for low-income women are below 50 percent across racial/ethnic groups and fall below the Healthy People 2000 goal of 60 percent (U.S. DHHS 1997). Yet for the 2.5 million health center women of childbearing age, their rates far exceed those of comparable women in the nation and meet or exceed the Healthy People 2000 goal (see Table 2).

For clinical breast examinations, health center women have rates around 80 percent, far exceeding the national rate for comparable women (62 percent). For up-to-date Pap smears, health center women not only exceed the national

TABLE 2 Proportion Receiving Up-to-Date Mammograms among Women at Health Centers and a National Health Interview Survey (NHIS) Comparison Group (in percentages)

Mammogram	*Health Center*	*NHIS Comparison*
Hispanic	76	48
White, non-Hispanic	58	44
Black, non-Hispanic	61	49
Other	73	[a]

Source: Adapted from the U.S. Department of Health and Human Services (1997) and the Bureau of Primary Health Care (1995).

a. Data not available.

comparable rate (75 percent), but they also exceed the 80 percent Healthy People 2000 goal (see Table 3). In addition, these up-to-date Pap smear rates exceed the goal for each racial/ethnic minority group (Regan, Lefkowitz, and Gaston 1999). Finally, the absence of racial/ethnic disparities in screening persists for health center patients receiving other conventional tests (see Table 3).

Cancer-screening rates for women do not seem to vary significantly by insurance status as they do in the general population (see Table 4). Health center screening examination rates seem to be impartial to income, insurance status, and race/ethnicity (Frick and Regan 2000; Carlson et al. 1999). Although health centers have not yet measured the health status of women diagnosed with breast cancer, their reduction and elimination of disparities in key screening examinations, while serving as a regular source of care for poor, uninsured people from racial/ethnic minority groups, are necessary precursors for future success at eliminating health status disparities.

Another measure of access to appropriate ambulatory care is the rate of hospitalization for potentially avoidable conditions, called ACSCs. Medicaid beneficiaries who seek care at health centers were 22 percent less likely to be hospitalized for such conditions than beneficiaries who obtain care elsewhere—14.7 percent for health centers and 18.9 percent for other Medicaid beneficiaries (Falik et al. 1998). Also, health center patients were 16 percent more likely to have outpatient visits for ACSC-associated conditions. As a result, health centers have demonstrated reductions in Medicaid costs of 30 percent to 34 percent, compared with patients receiving care elsewhere (Center for Health Policy Studies 1994).

TABLE 3 Health Center Screening by Race/Ethnicity (in percentages)

Race/Ethnicity	*Breast Exam*	*Mammogram*	*Pap Smear*	*Testicular Exam*	*Cholesterol Screening*
White	82	57	82	47	44
Non-white	79	64	84	48	46

Source: Adapted from Frick and Regan (2000).

TABLE 4 Up-to-Date Cancer Screening among Adult Health Center Women by Insurance Status (in percentages)

	Health Center[a]			*United States*[b]		
Insurance	*Pap Smear*	*Mammography*	*Breast Exam*	*Pap Smear*	*Mammography*	*Breast Exam*
Medicaid	93.4	65.6	88.0	41	38	52
Uninsured	88.2	55.9	79.0	32	19	38
Private/other insurance	91.6	56.2	83.1	58	55	62

Source: Adapted from Regan, Lefkowitz, and Gaston (1999) and Makuc, Freid, and Parsons (1994).

a. Pap smear within 1 to 3 years. Mammography and breast exams in the past 2 years.

b. Within the past year.

QUALITY OF CARE

Additional evidence of health center ability to provide access to appropriate care can be gleaned from its chronic disease management. Health center practices meet or significantly exceed literature-based standards for treatment of the most common conditions of hypertension, acute otitis media, diabetes, and asthma on over 80 percent of the care elements (Ulmer et al. 2000). Hypertensive health center African American and Hispanic patients report at a rate of 90 percent that their blood pressure is under control, more than three times that of a comparable group of hypertensives in the nation and nearly double the Healthy People 2000 goal of 50 percent (Mathematica Policy Research 1998b). Health center diabetics report that their glycohemoglobin rates are tested on schedule 43 percent of the time. Although this rate falls below the Healthy People 2000 goal of 60 percent, it is more than twice the rate reported in the literature (Mathematica Policy Research 1998a).

Other studies have measured the impact of the components of care delivered by health centers—availability of enabling services, presence of translation services, and access to on-site behavioral and mental health providers. Traditionally, insurance carriers inadequately reimburse for these services. These services are particularly critical for poor, uninsured people from racial/ethnic minority groups to assure their access to care. In a study of pregnant women who sought care at health centers, perinatal enabling services positively influenced timely infant and mother's postpartum visits. In addition, those health centers with behavioral and mental health services had significantly better rates of early entry into prenatal care (Lewis-Idema et al., Enabling Services, 1999). These results are noteworthy since health center prenatal care patients are twice as likely to be teenagers compared with the U.S. prenatal care population.

DISCUSSION

There are some limitations to this study. Patient interview surveys often have reporting and selection bias and are limited to patient recall and knowledge. Also, individuals may not be a reliable source for technical information regarding their health. However, by designing tools comparable to the NHIS, it is anticipated that these biases would be consistent across comparison groups. In addition, there are limitations in using Medicaid claims data since patient encounters in managed care arrangements are not included. Again, this bias is minimized by comparing Medicaid beneficiaries across several provider categories.

Additional data collection and evaluation activities must press for information about the health status of patients and of all people living in a health center catchment area. A health center sentinel network will be established to identify key health centers that are prepared to collect timely data on the health status of its patients and others living in the community. Obtaining information directly from the medical record will eliminate methodological weaknesses inherent in patient interview studies. Also, medical record information can more precisely measure patient health outcomes. In addition, the second user/visit survey will be launched to collect year 2000 data to compare the results with those presented here for 1995. All data collection activities will attempt to further discern disparities between racial/ethnic subgroups by oversampling those health centers that have appreciable proportions of their patient populations from subgroups within the conventionally used racial/ethnic groups. Health status disparities between racial/ethnic subgroups must not be camouflaged by the current method of aggregating data (Fiscella et al. 2000). Health centers will use the categories and subcategories currently advanced by the Bureau of the Census for its decenniel census.

Reducing the stubborn health care access and health status disparities of poor people from racial/ethnic minority groups and who are uninsured is a challenge to safety net providers (Rosenbaum et al. 2000; Institute of Medicine 2000). The results presented indicate the contribution of health centers in reducing these disparities, particularly the low birth weight disparity for African American infants and the racial/ethnic, income, and insurance status disparities for important preventive screening procedures. Health centers assist patients in obtaining and complying with care by providing interpreter services, cultural competence training, and targeted outreach programs, striving to serve as their patients' usual and regular source of primary care (Zuvekas, McNamara, and Bernstein 1999). The recorded improvements in health care access are likely to have an impact on health status.

Health centers serve 8.7 million of the approximately 43 million people without access to a private primary care provider, up from about 8.3 million in 1997. This pace is insufficient to meet the needs in a timely manner of the remaining 34 million living in underserved communities without access. As such, the nation needs a multipronged approach to achieve 100 percent access to primary care and narrow and eliminate the gap in health status.

First, it seems reasonable to continue to strengthen the existing health centers' safety net to assure that health care access and ultimately health status disparities among their patients are continually reduced and eventually eliminated. It also seems reasonable to expand existing networks to reach additional people currently without access. Finally, it remains a challenge to leverage scarce resources within communities of the remaining 34 million underserved to identify needs and develop systems that address those needs. Regardless of strategy or plan, the safety net of providers of care for vulnerable people needs to become their usual and regular source of care if the nation intends to reduce and eliminate health care access and health status disparities.

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Strengthening the US Health Care Safety Net

Nicole Lurie, MD, MSPH

CONTINUED INCREASES IN THE NUMBERS OF UNINSURED US citizens, increasing premiums for those who are insured, and the debate over prescription drug coverage[1] all have served to thrust the issue of access to health care on the national radar screen once again. Since the goal of universal health insurance seems less and less likely to be realized in the near future, much of the discussion has focused on the so-called safety net, which is the loosely knit health system that cares for those outside the traditional health care marketplace, who are primarily poor and uninsured. The mere existence of the safety net, let alone our nation's dependence on it, is evidence that the market does not distribute health care in a socially equitable manner. This often ad hoc (and unheralded) system is expected to provide access to care in geographically underserved areas and to address other barriers to care, such as social and cultural factors. With the increasingly diverse US population, additional factors include whether the patient and clinician can communicate in the same language and whether they understand and are comfortable with each other's cultures.

Because of the intrinsic links among access to care, quality, and outcomes, the safety net ideally should go beyond simply providing access to provide high-quality care to those it serves. The safety net functions against a backdrop of uninsurance and underinsurance and the inability of many who need care to pay for it. These problems are not distributed evenly across the population. Rural residents are more likely than those living in metropolitan areas to be uninsured.[1] Furthermore, recent increases in rates of uninsurance have affected population groups differentially. Between 1994 and 1998, the number of uninsured whites increased by 3.4% while the number of uninsured blacks and Hispanics increased by 17.4% and 21.5%, respectively.[2]

In addition to its shortcomings in providing affordable access to care, the market has been unsuccessful in distributing health care professionals to geographic areas according to need. Federal efforts, through community health centers and the National Health Service Corps (NHSC), have helped mitigate these market failures. In this issue of THE JOURNAL, Pathman and colleagues[3] present national data about the extent of nonfederal efforts to improve the distribution of the clinician workforce. They found that in 1996, 41 states had scholarship or loan repayment programs or other mechanisms to encourage medical practice in geographically underserved areas. They report that the combined number of clinicians who practice in underserved areas as a result of such programs is at least equal to that of the federal government's NHSC.

While the growth of such programs is undoubtedly a positive development, it must be put into context. The NHSC addresses only a small fraction of the unmet need, and even doubling that effort by adding those practitioners recruited by state programs still results in an inadequate number of practitioners needed for underserved areas. Indeed, the NHSC estimates the unmet need for clinicians at roughly 18000,[4] even after accounting for the practitioners identified in the study by Pathman et al.

Even if the safety net had an optimal geographic distribution of health care providers, concerns about its long-term viability would remain. The Institute of Medicine[5] recently identified 3 major factors that will hinder the ability of clinicians within the safety net to deliver high-quality care. First, these clinicians are likely to be disproportionately affected by the growing numbers of uninsured persons. Second, traditional subsidies that helped finance the safety net are eroding. Third, the rapid shift to Medicaid managed care has had adverse consequences for many providers within the safety net. While there is no direct evidence that the clinicians in programs studied by Pathman et al do, in fact, care for uninsured patients, it is well recognized that the areas in which they practice are more likely to have higher rates of uninsurance, so the demand to provide uncompensated or undercompensated care is likely to be greater than it is for other practitioners. If, in addition, the institutions that support these clinicians are increasingly under fiscal stress, their ability to develop or sustain an infrastructure to provide high-quality care is also threatened.

Beyond geographic distribution, social and cultural factors also have long been recognized as critical components of access to care. Sex, language, and race/ethnicity are all

See also p 2084.

Author Affiliation: US Department of Health and Human Services, Washington, DC.
Corresponding Author and Reprints: Nicole Lurie, MD, MSPH, US Department of Health and Human Services, 200 Independence Ave SW, Room 716-G, Washington, DC 20201.

recognized as important factors in this regard. Women's preferences for female physicians[6] and the challenges of recruiting female clinicians to underserved areas are well documented.[7] On another front, increasing evidence about health disparities points to differential treatment of minority patients in the health care system,[8] many of whom live in rural and urban underserved areas that are dependent on the safety net. Many areas contain large ethnic populations that are unable to communicate in English and have poorly understood health care beliefs that affect health care access and quality. Pathman et al do not describe the sex or ethnic composition of clinicians recruited to practice in state-sponsored safety net programs; to what extent there is concordance between clinicians and the populations they serve is not clear. However, such factors are increasingly understood to be important for patient satisfaction and health outcomes.[9,10]

From a policy perspective, it is critical to remember that the safety net is important not only to those who lack access to care, but also to the United States in general. For example, most uninsured persons are employed and constitute a workforce whose health and well-being is vital to US economic health. Furthermore, safety-net providers, supported by federal, state, and local resources, keep children immunized, enable adults to take care of their young children as well as their aging parents, treat and prevent the spread of infectious diseases, provide oral health and mental health services, and thus contribute to maintaining a strong social fabric. While not everyone is a direct user of safety-net services, the benefits of the safety net affect a range of groups and interests, including both the public and private sectors.

Pathman et al[3] focus on 2 of the major players—state and federal governments—and illustrate well how state initiatives can expand federal efforts to increase access. Such efforts are not limited to workforce policy and can be used to address multiple dimensions of access. State and local initiatives already expand access through providing health insurance to certain populations, the most notable being the State Children's Health Insurance Programs.[11] States and local communities can and often do take matters into their own hands, and further approach the ideal of universal health care coverage.[12] Some make insurance available and affordable to adults and families who have income above the limits for state programs and Medicaid. Others have formed networks of providers who will guarantee care for anyone who is uninsured or have used tax levies to fund universal coverage. State and local governments can complement federal efforts by creating revenue sources and encouraging partnerships to support an even wider range of activities to strengthen the safety net.

In addition to leveraging policy opportunities to expand coverage and care, state and local governments also can expand their roles in influencing the nature of the health professions workforce. The number of minority medical school graduates remains far behind their representation in the overall population.[13] The dramatic decline in minority medical school applicants over the past few years[14] suggests that this is another area in which the health care market has fallen short, requiring new approaches and new solutions. In addition to leveraging federal efforts to promote cultural competence[15] and language access,[16] states and local communities also can take steps to ensure that their clinician workforce reflects the ethnic characteristics of their populations. This will require a variety of creative mechanisms including recruitment of existing practitioners, development and support of diverse applicants to health professions schools, and reexamination of medical school admissions policies to shape a workforce that meets population needs.

Policy efforts also must strengthen the ability of safety-net practitioners to provide high-quality care. Many safety-net clinicians work in struggling practices that cannot afford the investment in infrastructure, such as information systems and distance technology, that can facilitate quality-improvement activities. The Community Access Program (CAP)[17] is a new federal program designed to strengthen the safety net by providing resources (such as developing information systems or creating language access programs) to better integrate networks of safety-net clinicians in communities around the country. The US Department of Health and Human Services (DHHS) has received more than 200 applications for CAP and has awarded 23 grants, a testament to the level of need and interest in strengthening the safety net. The total CAP budget is $25 million for 2001, and the DHHS hopes to expand the program in the future. State and local initiatives that support similar efforts can be important complements.

Finally, Pathman et al appropriately call for a mechanism to monitor programs that expand the workforce for underserved communities. This call is similar to a broader recommendation by the Institute of Medicine to do the same,[5] not just for the workforce, but for all components of the safety net. Until universal access to health care in the United States becomes a reality, such an endeavor will be critical for understanding how best to strengthen and support the safety net on behalf of the entire US population.

Disclaimer: The views expressed in this article are those of the author and do not necessarily reflect those of the US Department of Health and Human Services.

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Insuring the Uninsured

Time to End the Aura of Invisibility

Kevin Grumbach, MD

MOST PHYSICIANS HAVE THEIR STORIES. MINE DATES to one of my first nights on call as an intern in family medicine at San Francisco General Hospital in the summer of 1985. I was summoned to the emergency department to admit a young woman with a presumptive diagnosis of subacute bacterial endocarditis. For a new intern at that stage of unspoiled eagerness when the very act of wearing a pager instills a noble sense of professional duty, this type of call made me hasten to the emergency department in excited anticipation of encountering a patient with a classic but rare disease. Indeed, the patient had all the textbook characteristics of the infection: rheumatic fever in her youth, recent weeks of malaise and low-grade fevers, a holosystolic murmur, and blood cultures sent from clinic 2 days earlier growing chains of gram-positive cocci.

I explained to the patient the likely diagnosis and need for hospitalization. Her anxious expression intensified into one of panic. "Don't worry," I reassured her. "We have excellent antibiotics that can cure this disease. I am confident we can make you well."

"But I don't have insurance," she replied. "I can't pay the hospital bill. They'll take my house. I won't stay in the hospital."

I was dumbfounded. My medical school courses had taught me how to manage subacute bacterial endocarditis. But nothing in my medical education had prepared me to treat the terrible American disease of deficiency of health insurance.

This young woman was typical of many uninsured Americans. She worked full-time, but in one of those permanently "temporary" job classifications that made her ineligible for benefits from her employer. She had legally immigrated to the US many years earlier. Her husband was a self-employed truck driver. The patient and her husband earned a modest family income, and had saved enough money to have just purchased a small house in anticipation of having children. Suddenly, the tragedy of her serious illness was compounded by the terror of potential financial ruin and loss of her home.

Most physicians have similar stories. Stories of the anguished look in the eyes of a patient who does not know where the money will come from to pay for a pharmacy bill. Stories of the patient with advanced stage breast cancer who never followed through on obtaining the mammogram ordered years earlier because she did not have insurance. Stories that define in starkly human terms the problems of access to care and the egregious inequity of the US health system.

From the Aura of Inevitability to the Aura of Invisibility

In the years following my personal introduction to the plight of the uninsured, the medical profession and the nation visibly struggled to confront and remedy these systemic problems. In 1991, *JAMA* published the first of its theme issues devoted to the problems of the uninsured and underinsured. The following year, public support for health care reform helped to carry Bill Clinton into office as president. As the momentum for change grew, Americans no longer asked "Will we have universal health care?" but "What type of universal system will we have?" Then abruptly, in the summer of 1994, health care reform imploded. The Clinton health plan was dead on arrival in Congress. In California, voters rejected a ballot initiative sponsored by a grass-roots coalition that sought to establish a single-payer state health plan.

Exhaustive analyses of the failed universal health care proposals in the United States identified myriad reasons for their

Author Affiliation: Department of Family and Community Medicine, University of California, San Francisco.
Corresponding Author and Reprints: Kevin Grumbach, MD, San Francisco General Hospital, Ward 83, 1001 Potrero Ave, San Francisco, CA 94110 (e-mail: keving@itsa.ucsf.edu).

U.S. Department of Health and Human Services
HRSA BPHC Bureau of Primary Health Care
Health Resources and Services Administration

Visioning the Future in Primary Care: Creating a New Model to Reach 100% Access and 0 Health Disparities

Comprehensive, Community-Based Health Service Delivery

The People We Serve ... The People We are

Creating a New Model to Reach 100% Access and 0 Health Disparities

A Model That Works for the Health of All Americans

Overview

This paper introduces a model of primary health care that provides every community member the right services at the right time in the right way. It fulfills a national and community-based mandate for a health care delivery system that:

- Integrates current best practices
- Links with entitlement programs
- Leverages financing structures
- Restructures other community assets

Benefits

Implementation of this model will result in healthier individuals, healthier populations, and thriving communities. It is meant to give us all a target that is adaptable to any given marketplace or community but which achieves a common standard of care.

Everyone in America will have access to, regularly use, and be satisfied with comprehensive, cost-effective, high-quality, primary health services that support optimal quality of life. We will reach 100% access to primary health care services for all with zero racial and ethnic health disparities. Differences between people, such as culture, class, educational attainment, employment status, and who pays for health care, will no longer be associated with differential health outcomes.

The power of this vision is that it begins and ends at the community level. It rests on the primary care principles of prevention, early detection, and appropriate intervention. Finally, it puts us all on a path in the same direction, recognizing that our pace may vary, as will how and when we reach our destination.

Delivery of Care in Current Systems

Becoming a Patient: Today, the patient seeking services at a point of access initiates most medical care delivery. Services are usually provided by physicians and delivered in brief periods of time. If a person does not recognize signs, symptoms, or risk of disease, no care is sought and none provided.

Provider Response: Providers usually view only those people they have seen, or who are contractually assigned to their practice, as being under their care responsibility. Services to the remainder of the community, when they are provided, are rationalized as a public service (uncompensated care), or as focused efforts to increase market share. A subgroup of the population, therefore, does not receive care.

Managed Care: Efforts to expand care within populations have been made by managed care organizations but with mixed success. While patients have received more preventive services using a managed care model, cost considerations often limit access for acute and chronic disease care. A misalignment of incentives among managed care companies, providers, and patients accounts for the bulk of dissatisfaction with the managed care system as it currently exists.

The Acute Care Model: The majority of current medical care in the United States is provided by, or under the responsibility of, professionals trained in allopathic or osteopathic medicine regulated by State boards of medicine under the laws of the State and Federal government. A typical medical encounter occurs in an office, clinic, or hospital setting and revolves around a problem or complaint identified by the patient. The provider generally manages these encounters in intervals of approximately 15 minutes. The provider frequently has an inadequate database concerning the patient, and most of the interaction is often spent obtaining information. The provider gives advice, usually in the form of ordering diagnostic testing or treatment, with minimal explanation to the patient. The nature of this traditional structure favors acute care over chronic or preventive care.

This typical provider visit is not structured to systematically address the needs of multiple chronic conditions as well as acute illness care. Nor does this brief encounter permit time to:

(1) explore and address relevant psychosocial aspects of the patient's illness
or
(2) review the patient's record regarding the need for preventive care.

There are other health care resources in a community that can intervene. The use of ancillary services and roles expands access and increases opportunities for patient-focused care. The overall amount of time devoted to each patient becomes appropriate to the need, increasing the number of services provided at greater convenience for the patient. Such increase in services may increase overall costs, but the unit cost and long term per person health care expense will decrease as health outcomes improve.

Delivery of health care in this vision requires community-wide commitment and involvement.

Payment sources and care delivery components assume joint responsibility to provide appropriate health care at fair compensation that results in optimal satisfaction with service and optimal health care outcomes for the entire population in that community.

Key Principles of the "Comprehensive Community-Based Health Service Delivery Model"

- The system serves the **universal population** of the service area in order to prevent disparities of outcome. The universal population includes all persons within the service delivery area, including both permanent and transient individuals.
- The community-based health care teams address all the **health needs** of the population. The health needs of the population include preventive services, early diagnosis and treatment, acute and chronic care, mental health, dental, and other care on an inpatient and outpatient basis as deemed appropriate by the clinical team.
- The population being served has access to care on demand – when they believe they need it, at hours and locations convenient to them.
- The care occurs within a cultural framework appropriate to the patient.
- Patients have a role and responsibility to aid and actively participate in their care.
- Patients have the right to make free and informed decisions regarding treatment modalities including the right to refuse treatment.
- The costs of care provided are within achievable ranges and distributed equitably and responsibly.

The Vision Achieved

The culmination of the vision is a health care delivery system that provides every community member the right services at the right time in the right way.

While the health care needs of populations and individuals are identifiable within current care systems, the delivery systems fail to provide necessary, timely, and appropriate services.

The keys to fulfilling a national and community-based mandate for a health care delivery system that serves all are:

- Integration of current best practices
- Linkage with entitlement programs
- Leveraging financing structures
- Restructuring of other community assets

This vision recognizes a community-wide responsibility to provide health care. As needs and services are identified and met in a socially, scientifically, and culturally appropriate environment, *healthy individuals become healthy populations and thriving communities.*

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DR. LARA *is Assistant Professor of Pediatrics, UCLA Division of General Pediatrics and Director, UCLA/RAND Program on Latino Children with Asthma, RAND Health, 1700 Main Street, PO Box 2138, Santa Monica, CA 90407;* MS. ALLEN, *was a Research Associate at the time this article was written; and* DR. LANGE *is Research Coordinator, Center for Healthier Children, Families, and Communities, UCLA School of Public Health, Center for Health Sciences 61-254, Los Angeles, CA 90095.*

THE THREE LEADING CAUSES OF DEATH IN AFRICAN AMERICANS: BARRIERS TO REDUCING EXCESS DISPARITY AND TO IMPROVING HEALTH BEHAVIORS

ROBERT H. L. FELDMAN, PhD
ROBINSON FULWOOD, MSPH
University of Maryland, College Park

Abstract: African Americans suffer disproportionately from several major health problems associated with high morbidity and mortality. The 1985 DHHS Secretary's Task Force Report on Blacks and Other Minorities identified six major disease categories of excess deaths for African Americans compared with whites by applying the lower death rate for whites to the American population. The report provided a stimulus for public and private action to begin to address the health disparities between minority and nonminority populations. This article examines three of the leading causes of death for African Americans and assesses the extent to which the health disparity between African Americans and whites has been reduced. The three leading causes of death for African American males are diseases of the heart, cancer, and HIV infection/AIDS. The conditions are the same for African American females except stroke replaces HIV infection. Three health outcomes measures are discussed: life expectancy, excess death rates, and years of potential life lost. A widening of the gap between the races was found for diseases of the heart and HIV infection for males and for cancer for females. An extensive list of barriers to reducing the disparity are presented from the scientific literature and strategies for reducing the three health problems are recommended.

Key words: African Americans, barriers, excess deaths, health status, health behavior, HIV/AIDS, cardiovascular disease, cancer, risk factors.

African Americans are the largest minority group in the United States, comprising 12.6 percent of the population.[1] Nearly 59 percent of all African Americans live in central cities characterized by crowded housing, unemployment, exposure to a pervasive drug culture, periodic street violence, and generally high levels of stress and poverty.[2] African Americans are a fairly young

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population, with a median age of 24.9 years. The average size of the African American family is about 3.7 members, which is larger than that of the general population. While 79 percent of African Americans have completed high school, only about 13 percent are college graduates. African Americans are disproportionately affected by several major health problems that cause premature disability and death. The life expectancy and the years of healthy life that African Americans experience are significantly lower than that of the U.S. white population.[3]

The determinants of the differentials in health status measures are multifaceted. However, many studies have associated adverse health outcomes in African Americans with poverty, inadequate access to medical care, discrimination, overcrowding, stressful life events, and a variety of risk factors.[2,4-8] For African Americans, achieving healthier lives may depend on the adoption of healthy lifestyle behaviors on an individual, as well as a community-wide, basis[6-8] to facilitate significant reductions in both chronic and infectious diseases.

In 1985, the U.S. Department of Health and Human Services (DHHS) Secretary's Task Force report on blacks and other minorities[8] identified six major areas of excess mortality for African Americans as compared with whites. This report provided a basis for the federal government to establish programs to reduce disparities between minority and nonminority populations. Consequently, health promotion and disease prevention activities have focused on closing the gap in excess deaths experienced by the African American population.[7]

Since the development of the task force report,[8] an important question that has been raised is whether there has been a decrease in the excess disparity between African Americans and whites for major health conditions. To examine this question, this study compared mortality rates of African American males and females with their white counterparts with respect to the three leading causes of death among African Americans. The three leading causes of death for African American males are diseases of the heart, cancer, and HIV infection. Among African American females, stroke replaces HIV infection as the third leading cause. Before analyzing the relevant data, the following review of the literature provides insights about the impact and burden of these conditions on the African American population.

Cardiovascular disease. The major forms of cardiovascular disease (CVD) are coronary heart disease (CHD) and stroke, each of which will be addressed separately. A decline in mortality from CVD over the past 30 years has been well documented, but the reasons for the decline remain unclear.[9-10] Improvement in the reduction of CVD risk factors since the 1970s may have been an important contributor to the 60 percent decline in mortality as compared with the rate in the 1950s. The decline in the incidence of CVD and improved medical interventions may have also contributed to the decline in mortality. In addition, the decreasing trend may be attributable, in part, to the decline in major risk factors such as hypertension, smoking, and elevated serum cholesterol, at least in certain segments of the population.[9-10] As such, researchers and clinicians have gained a better understanding of the ways in which CVD risk can be modified to foster a continued decline.[11]

Consequently, the CVD mortality rate has declined dramatically in African Americans in the United States. In a 1985 study of an urban population,[12] investigators determined that the decline was due to a reduction in CVD risk factors. They compared risk factors in an urban black population between the ages of 35 and 69 with those obtained in urban African Americans between the years 1973 and 1974. They found that age-adjusted body mass index (BMI) and prevalence of overweight increased significantly over the 12-year period in both males and females. Mean systolic blood pressure declined significantly for both sexes, diastolic blood pressure declined significantly in males, and the proportion of male and female hypertensives on medication and with disease under control increased.

Although the overall prevalence of smoking changed only slightly, the proportion of heavy smokers decreased significantly in males. The age-adjusted heart disease mortality rates in African Americans fell 27 percent between 1968-1973 and 1979-1984, and stroke mortality fell 58 percent. Therefore, declines in prevalence of risk factors with the exception of overweight may be contributing to declining CVD mortality rates in African Americans.[12]

In a cohort study of medical students from the classes of 1958 through 1965 at Meharry Medical College and the classes of 1957 through 1964 at Johns Hopkins University, at baseline, African Americans were found to be older, to be more likely to smoke, and to have greater BMI and higher systolic blood pressure. At follow-up, the African American physicians from Meharry had higher CVD risk, higher incidence of coronary artery disease, and much higher case fatality.[13] The study suggests that risk factor levels in youth can predict CVD events several years later. The best predictors of increased risk were cigarette smoking, cholesterol, paternal history in white physicians, and blood pressure in African Americans.

Coronary heart disease. African Americans develop CHD earlier than whites, and the disease results in more deaths in the former group. Because multiple risk factors and risk factor clustering are common in African Americans, efforts at primary and secondary prevention in this population need to address the total risk-profile.[14] In the Charleston Heart Study, a 30-year follow-up study,[15] researchers found that a higher level of education was predictive of lower mortality rates due to CHD among white males and African American females. For all causes of death, the rates for African Americans were higher than those for whites. They concluded that the major risk factors for mortality from CHD were similar in African Americans and whites.

In another study, Wild and colleagues[16] compared CHD and stroke death rates in six ethnic groups, including African Americans, using California census data and death data from 1985 to 1990. African American males and females in all age groups had the highest death rates from CHD and stroke. In

a study using data from the 1986 National Mortality Follow Back Survey, the 1985 National Health Interview Survey, and the U.S. Bureau of the Census[17], investigators assessed risk factors for sudden, nonsudden, and other CHD death between whites and African Americans in relation to known risk factors for CHD and socioeconomic status (SES). They found that African American males between the ages of 25 and 44 and females between the ages of 25 and 54 had about twice the risk of sudden, nonsudden, or CHD death as did whites. Interestingly, they also found that half or more of all excess risk for African Americans could be explained by SES, and that 18 percent of excess sudden CHD death could be further explained by modifiable CHD risk factors such as cigarette smoking, body weight, diabetes, and hypertension.[17]

Stroke. As the U.S. minority population continues to increase, more nonwhite citizens are at risk of stroke.[18] In particular, African Americans are known to experience an excess of stroke mortality as compared with whites. This important issue continues to be the subject of research. For example, in the Longitudinal Mortality Study,[19] researchers found that excess stroke mortality in African Americans mainly occurred between the ages of 45 and 55 years. Moreover, in the first National Health and Nutrition Examination Survey Epidemiologic Follow-up Study,[20] investigators found that African Americans between the ages of 35 and 44 years were at significantly increased risk for stroke as compared with whites. However, older African Americans (64 and older) were not at increased risk. The investigators concluded that much of the increased risk for stroke experienced by African Americans can be explained by their higher prevalence of stroke risk factors, especially diabetes, hypertension, and lower educational attainment. The authors also pointed out that younger African Americans may still be at increased risk after adjusting for stroke risk factors.[20]

To investigate cross-sectional differences in sociodemographic and stroke risk factors, investigators prospectively evaluated patients older than age 39 from Northern Manhattan hospitalized for acute ischemic stroke.[21] Thirty-five percent of the patients were African American. African Americans in the sample were younger than whites and were more likely to have fewer than 12 years of education. The researchers found that hypertension was more prevalent in African Americans with stroke than in whites, and it was often untreated. In addition, African American females were significantly more obese than white females in the sample. Heavy alcohol use and cigarette smoking were more often reported by African Americans. Moreover, African Americans were less likely than whites to have visited a physician one year after the stroke. The investigators concluded that these differences suggested that the burden of risk factors was increased in African Americans with stroke.[21]

In another study of stroke,[22] African Americans were found to have a threefold to fourfold increased stroke mortality relative to non-Hispanic Whites at younger ages. However, at older ages, when stroke mortality is the highest, the stroke mortality rate in non-Hispanic whites approached the stroke mortality rate of African Americans. The authors concluded that measures to prevent stroke mortality should emphasize its predilection for young African Americans.

Risk factors. There is a body of research that supports the association of risk factors with CVD morbidity and mortality. Hypertension is a powerful independent risk factor for CVD morbidity and mortality. The treatment of hypertension in African Americans is often complicated by a variety of factors.[23] These include the tendency of the African American hypertensive patient to experience three to five times the CVD mortality of the White hypertensive patient, more frequent progression to end-organ damage and stroke, and SES conditions that impede access to proper health care.

Cigarette smoking and physical inactivity are also well established behavioral risk factors of CVD. In a population-based study where physical activity was used to modify mortality associated with smoking,[24] mortality rates for smokers during the 25-year follow-up were strongly related to daily number of cigarettes smoked. Physically active males had lower overall risk and cardiovascular risk than did sedentary males. Furthermore, physically active males who never smoked had the lowest death rate, while physically inactive smokers had the highest rate.

However, vigorous exercise in smokers was associated with an almost 40 percent lower CVD mortality rate. The investigators concluded that regular physical activity was associated with lower total and CVD mortality rates. Similar effects were observed in both smokers and nonsmokers.[24] The association of smoking, serum cholesterol, and blood pressure with CHD mortality and the contribution of changes in risk factors to the decline in CHD mortality were assessed in three cohort studies of middle-aged populations examined in 1972, 1977, and 1982 in Eastern Finland.[25] The investigators found that age-adjusted mortality decreased for both males and females. The decrease was associated with a marked decrease in CVD risk factors. Also, nearly half of the decrease in CHD mortality was associated with changes in risk factors. Smoking also increases CVD risk at any level of blood pressure for CHD, stroke, and cardiac failure.[26]

In addition, data from the Framingham Heart Study[26] showed a prompt halving of the CHD risk in those who gave up smoking compared with those who continued to smoke, regardless of the duration of the habit. The investigators found that hypertensive individuals who smoke one pack a day could quickly reduce their risk by 35 to 40 percent by not smoking. In general, these studies provide important evidence for the link and impact of risk factors to CVD risk even though the studies did not target African Americans.

Cancer. Cancer research has shown that African American males have the greatest risk of dying from cancer, followed by white males. White females have the lowest overall cancer mortality rate.[27] In addition, African American

males have a higher incidence and a lower survival rate from most cancers, particularly prostate cancer, the leading cause of cancer deaths for African American males and white males followed by cancer of the lung and bronchus. For African American females and white females, breast cancer is the leading cause of cancer deaths, followed by colon and rectal/lung and bronchus cancer for African American females and lung and bronchus cancer/colon and rectal cancer for white females. However, white females have the lowest overall cancer mortality rates.

Trends in prostate cancer indicate striking racial/ethnic variations: the incidence rate among African American males is more than seven times that of some other ethnic groups.[27] Although the incidence among whites is quite high, it is distinctly lower than among African Americans. Males with a family history of prostate cancer are at increased risk, but whether this is due to genetic or environmental influences, or both, is not completely known. In a study of African American males' perception of prostate cancer,[28] investigators found that subjects did not identify trouble urinating, pain urinating, or blood in the urine as signs of prostate cancer. In addition, fewer than half of the subjects knew at what age one should start to have prostate examinations, and 40 percent did not believe they were more likely than most males to develop prostate cancer. Almost 60 percent did not know African American males were more likely than white males to develop prostate cancer, whereas 45 percent thought that if they had prostate cancer it would kill them, and another 28 percent were not certain.[28]

Awareness of risk factors associated with other forms of cancers vary. For example, in a study of colorectal cancer in a disadvantaged population, Price[29] found that at least 20 percent of the respondents incorrectly believed that homosexual males were more likely to develop bowel cancer, exercising regularly would not affect bowel cancer, bowel cancer did not run in families, and eating foods high in fat did not increase bowel cancer risks. In addition, the investigator found that the majority of the respondents (54 percent) did not believe that fecal occult blood tests could help save their lives if they had bowel cancer since 90 percent perceived bowel cancer as incurable even if caught early.[29]

Breast cancer is the most common form of cancer among females in the United States.[27] The incidence of breast cancer has been rising for the past two decades, while mortality has remained relatively stable since the 1950s. Much of the incidence in the past 15 years for African Americans females is due to an increase in detection (screening) by physical examination and mammography.[30] Mortality rates are much lower than incidence rates, with the highest age-adjusted mortality occurring among African American females. The important risk factors for breast cancer include early age at onset of menarche, late age of onset of menopause, first full-term pregnancy after age 30, history of premenopausal breast cancer for mother and sister, and a personal history of breast cancer or of a benign proliferative breast disease. Urban residence, nulliparity, and obesity have also been shown to be associated with breast cancer.[27]

In a study of urban African American females who wanted mammography and those who did not, Price and colleagues[31] found that both groups of inner-city females had poor knowledge of mammography. Those who wanted a mammogram perceived themselves as more susceptible to breast cancer and considered breast cancer more severe than those who did not want a mammogram. About 85 percent of both groups agreed that they would receive a mammogram if they were told to by their physicians. The racial difference in breast cancer survival rates for females may exist because African American females have tumors that are more advanced at the time of diagnosis, because tumor biology in African American females is different than in white females, and because of confounding comorbid conditions and SES factors.[32]

In a study by Jacob and colleagues,[33] the investigators assessed reported frequency of breast self-examination (BSE), knowledge of the technique, and attitudes regarding BSE of 180 African American females. They found that most respondents reported practicing BSE during the previous year, and 50 percent reported practicing monthly or more often. Less than half of the sample indicated performing BSE according to the American Cancer Society guidelines, although 92 percent reported being either very confident or somewhat confident of their performance. In general, BSE performers were older, had higher incomes, and were more likely to believe in the benefits of BSE, to perceive social approval of BSE practices, to have been taught to perform BSE, to have had a Pap smear, and to be more likely to have had a general physical exam within one year.[33]

In another study, 500 economically disadvantaged females were assessed regarding their perceptions and screening of breast cancer.[34] The investigators found that those who were more knowledgeable about breast cancer were significantly more likely than the least knowledgeable to perceive themselves as more susceptible to breast cancer, to perceive breast cancer as less severe, to perceive fewer barriers, and to perceive more benefits to breast cancer screening. In a corollary study,[35] investigators found that the majority of females were aware that sidestream smoke and air pollution are lung cancer risk factors. However, 41 percent felt that there was nothing people could do to decrease their risk of developing lung cancer. Thirteen percent perceived themselves as more susceptible to lung cancer than others of the same age and sex, although 20 percent believed that low SES people were more likely to develop lung cancer than higher SES people. In addition, 25 percent believed that almost everyone who develops lung cancer dies of it within five years.[35]

Human Immunodeficiency Virus Infection/Acquired Immunodeficiency Syndrome. The incidence of HIV/AIDS is increasing in the African American heterosexual community.[3] Even though African Americans represent only 12.6 percent of the U.S. population, they comprise 28 percent of the people with AIDS. African American adolescents are threatened by AIDS

because of their high-risk sexual behavior. Since no cure exists at the present time, teaching people how not to become infected is the only strategy for reducing the spread of AIDS.[36] In a study of African Americans adolescent males,[37] assignment was made to receive AIDS risk education intervention aimed at increasing AIDS knowledge and weakening problematic attitudes toward risky sexual behavior or to receive a control intervention on career opportunities. The subjects who received AIDS education had greater AIDS knowledge, less favorable attitudes toward risky sexual behavior, and lower intentions to engage in risky behavior than did those in the control group. After three months, the intervention group reported fewer occasions of coitus, fewer coitus partners, greater use of condoms, and a lower incidence of heterosexual anal intercourse than did adolescents in the control group.[37]

In a survey of inner-city adolescents in New York City,[38] knowledge, attitudes, beliefs, and behaviors concerning AIDS were assessed. Sexual activity was the major risk factor for AIDS in this population; 58 percent of the adolescents had engaged in sexual intercourse; 12 percent of them had never used contraception. None had used intravenous (IV) drugs. Knowledge of HIV transmission was generally good, although there were misconceptions. For example, 52 percent believed that donating blood could transmit HIV. Thirty-nine percent did report behavioral change in the previous six months because of concern about AIDS. Of those reporting change, 66 percent reported using condoms, and 16 percent claimed to abstain from sex. Of African American female adolescents, 71 percent were sexually active.[38] In a review of several published reports describing behavioral changes in response to the threat of AIDS,[39] investigators found that these studies demonstrated rapid, profound, but expectably incomplete alterations in the behavior of both homosexual/ bisexual males and IV drug users. The authors conclude that future studies should address much needed information about the determinants as well as the magnitude of behavioral change required to reduce the further spread of AIDS.

In a group of multiethnic school-age children,[40] investigators found a high degree of confusion about HIV/AIDS risk. They assessed how much seventh graders knew about AIDS and AIDS risk and tried to identify areas of confusion that might serve as important targets of educational intervention. Consistent with older adolescents, the investigators found that young adolescents had a high degree of knowledge about AIDS and AIDS risk; however, there was considerably less known about two areas relating to AIDS risk. Specifically, 31 percent of adolescents did not correctly identify abstinence as the most effective way of preventing AIDS, and 33 percent believed that AIDS could be spread through casual contact.[40]

Another area of concern in the spread of HIV infection is the behavior of IV drug users. More than 8 of 20 IV drug users infected with HIV are African American or Hispanic. Recognizing the sociocultural factors associated with transmission, public health officials have called for interventions designed for ethnic/racial minority groups.[41] In a study of sexual behavior and attitudes toward safe sex involving recovering IV drug users,[42] the investigators found that reported condom use was low; males tended to report rates of sexual risk-taking behavior, while females reported strategies to reduce risk behavior associated with HIV transmission. IV drug users have an addiction and a subculture that make risk education difficult. Therefore, the facilitation of health behavior change may require more than simple education. It may mean changing IV drug users' subculture as well as implementing long-term efforts to reduce the spread of HIV among drug users; otherwise, programs are not likely to be effective.[43-44]

In a sample of 162 asymptomatic gay males and bisexual males,[45] investigators examined the pattern of changes and stability in sexual behavior. The data revealed that while the large majority (84 percent) had at least modified their sexual behavior, primarily in the form of reducing their total number of partners and their number of anonymous partners, a significant proportion (48 percent) continued to engage in risky sexual behavior despite high levels of awareness of risk reduction guidelines. The researchers noted that information alone is not sufficient to induce the desired behavior changes in a substantial proportion of gay males.

In another study, 104 gay males with a history of frequent AIDS high-risk behavior were randomly assigned to treatment and control groups.[46] The intervention group was provided AIDS risk education, cognitive-behavioral self-management training, sexual assertion training, and self-affirming social support. They found that the intervention participants greatly reduced their frequency of high-risk sexual practices and increased their behavioral skills for reducing sexual coercion, AIDS risk knowledge, and adoption of safer sex practices. The changes were still maintained eight months later.[46] In fact, Fisher and Fisher[47] found that a conceptually based, highly generalizable model of promoting AIDS risk reduction is a function of people's information about AIDS transmission and prevention, their motivation to reduce AIDS risk, and their behavioral skills for performing specific acts involved in risk reduction.

The purpose of this article is to assess progress toward reducing the disparity in three measures of health status with respect to the three leading causes of death for African Americans as compared with whites and to identify barriers from the research literature that may contribute to the excess disparity between the two groups. The three leading causes of death among African Americans are diseases of the heart, cancer, and HIV infection for African American males, and diseases of the heart, cancer, and stroke for African American females. The three measures of disparity are average life expectancy, excess death rate, and years of potential life lost (YPLL).

Methods

Data from the National Center for Health Statistics (NCHS), the federal agency responsible for the collection of health statistics on the U.S. population,

was analyzed for African Americans compared with whites. This article will present the following: change in life expectancy for African Americans as compared with whites between 1985 and 1995; change in excess death rate for African Americans as compared with whites between 1985 and 1995 for diseases of the heart, cancer, and stroke (females only), and between 1987 and 1995 for HIV infection (males only); change in YPLL for African Americans as compared with whites between 1985 and 1995 for diseases of the heart, cancer, and stroke (females only), and between 1990 and 1995 for HIV infection (males only); barriers to reducing the gap in the three major health problems between African Americans and whites.

The following parameters were calculated: (1) difference in life expectancy between African Americans and whites, (2) difference in excess age-adjusted death rates between African Americans and whites, (3) difference in excess age-adjusted YPLL between African Americans and whites, (4) percentage change in average life expectancy, (5) percentage change in excess age-adjusted death rates, and (6) percentage change in excess age-ajusted YPLL between African Americans and whites. The intent of this article is to be descriptive. Therefore, no attempt is made to test hypotheses in the comparison of statistics.

Source of data. The data in this report are based on information from all death certificates filed in the 50 states and the District of Columbia. Mortality statistics are based on information coded by the states and provided to NCHS through the Vital Statistics Cooperative Program and from copies of the original certificates received by NCHS. Data for the entire United States refer to events occurring within the United States. The mortality statistics presented here were compiled in accordance with World Health Organization (WHO) regulations, which specify that member nations classify causes of death by the current *Manual of the International Classification of Diseases (ICD), Injuries, and Causes of Death.*[48] Tabulations of cause-of-death statistics are based solely on the underlying cause of death. The underlying cause of death is defined by WHO as the disease or injury that initiated the sequence of events leading to death or as the circumstances of the accident or violence that produced the fatal injury. It is selected from the condition entered by the physician in the cause-of-death section of the death certificate. When more than one cause or condition is entered by the physician, the underlying cause is determined by the sequence of conditions on the certificate, provisions of the ICD, and associated selection rules.

For HIV infection, beginning in 1987, the NCHS introduced categories for classifying and coding deaths classified as "immunodeficiency virus (HIV) infection." Before 1987, deaths involving HIV infection were classified as "Deficiency of cell-mediated immunity," contained in the category "All other diseases," to "Pneumocystosis," contained in the category "All other infection and parasitic diseases," to "Malignant neoplasms, including neoplasms of lymphatic and hematopoietic tissues," and to a number of other causes. Thus, the comparison mortality data for HIV infection in this study will be between 1987 and 1995.

Results

As shown in Table 1, the three leading causes of death in 1995 for African American males were diseases of the heart, cancer (malignant neoplasms), and HIV infection. These conditions accounted for about 55 percent of the deaths in African American males. The two leading causes of death were the same for African American females and African American males; however, the third leading cause among females was stroke (cerebrovascular diseases). These three conditions accounted for about 59 percent of the deaths for African American females. The corresponding values were about 59 percent for white males and about 65 percent for white females. However, as shown in Table 2, when the death rates were age-adjusted, African American males and females had higher death rates than did white males and females, respectively. In 1985, the overall age-adjusted rates were 1,053.4 and 693.3 per 100,000 population for African American males and white males, respectively, and 594.8 and 391.0 per 100,000 population for African American females and white females, respectively. However, in 1995, the rates had declined. The age-adjusted rates were 1,016.7 and 610.5 per 100,000 population for African American males and white males, respectively, and 571 and 364.9 per 100,000 population of African American females and white females, respectively.

Between 1985 and 1995, the overall age-adjusted death rates decreased for each of the four race-sex groups. However, the percentage declines were greater for whites than for African Americans. The age-adjusted death rate declined 11.9 percent for white males compared with 3.5 percent for African American males. The age-adjusted death rate declined 6.7 percent for white females compared with 4.0 percent for African American females (see Table 2).

Average life expectancy. Table 3 shows the average life expectancy at birth and at age 65. In 1985, the average life expectancy at birth for African American males was 65 years, 6.8 years fewer than that of white males. The average life expectancy was 73.4 years for African American females, 5.3 years fewer than that for white females. In 1995, the difference in average life expectancy between African Americans and Whites increased regardless of sex. The racial difference in average life expectancy increased to 8.2 years between African males and white males and 5.7 years between African American females and white females. Between 1985 and 1995, African American males experienced the smallest increase in average life expectancy (+0.2 years), followed by African American females (+0.5 years) and white females (+0.9 years). White males had the largest increase in average life expectancy (+1.6 years).

At age 65, the racial difference in life expectancy regardless of sex was about two years, with whites continuing to live slightly longer, as shown in Table 3. In addition, between 1985 and 1995, the average life expectancy increased for

TABLE 1
THE THREE LEADING CAUSES OF DEATH AND NUMBER OF DEATHS BY RACE AND SEX IN THE UNITED STATES, 1995

	AFRICAN AMERICAN	PERCENTAGE	WHITE	PERCENTAGE
Males				
All causes	154,175	100.0	997,277	100.0
1. Heart diseases	38,389	24.9	318,750	32.0
2. Malignant neoplasms	32,880	21.3	244,000	24.5
3. HIV infection	12,875	8.4	22,670	2.3
Total three causes	84,144	54.6	585,420	58.7
Females				
All causes	132,226	100.0	990,160	100.0
1. Heart diseases	40,254	30.4	330,338	33.4
2. Malignant neoplasms	27,723	21.0	224,897	22.7
3. Cerebrovascular disease	10,526	8.0	84,436	8.5
Total three causes	78,503	59.4	639,671	64.6

Source: U.S. DHHS: NCHS: Monthly vital statistics report: Vol. 45, No. 11, Supplement 2, 1997.

TABLE 2
THE AGE-ADJUSTED DEATHS RATES AND PERCENTAGE CHANGE BY RACE AND SEX IN THE UNITED STATES, 1985 AND 1995

	1985	1995	PERCENTAGE CHANGE
African American males	1,053.4	1,016.7	–3.5
White males	693.3	610.5	–11.9
African American females	594.8	571.0	–4.0
White females	391.0	364.9	–6.7

Source: U.S. DHHS: NCHS: Monthly vital statistics report: Vol. 45, No. 11, Supplement 2, 1997.

all race-sex groups. African American females experienced the smallest increase (+0.2 years), followed by white females (+0.4 years) and African American males (+0.6 years). White males had the largest increase in average life expectancy of 1.2 years (see Table 3).

Excess death rates. The differences in the age-adjusted death rates for African Americans as compared with whites in 1985 for the three leading causes of deaths are shown in Table 4. The differences are referred to as "excess" death rates. For diseases of the heart, African American males experienced an excess death rate of 64.6 per 100,000 population when compared with white males. African American females experienced an excess death rate of 66.6 per 100,000

TABLE 3
AVERAGE LIFE EXPECTANCY (IN YEARS) AT BIRTH AND AT AGE 65 AND DIFFERENCE BETWEEN RACE-SEX GROUPS IN THE UNITED STATES, 1985 AND 1995

	MALES			FEMALES		
	AFRICAN AMERICAN	WHITE	DIFFERENCE	AFRICAN AMERICAN	WHITE	DIFFERENCE
At birth						
1985	65.0	71.8	–6.8	73.4	78.7	–5.3
1995	65.2	73.4	–8.2	73.9	79.6	–5.7
Difference	+0.2	+1.6		+0.5	+0.9	
At age 65						
1985	13.0	14.5	–1.5	16.9	18.7	–1.8
1995	13.6	15.7	–2.1	17.1	19.1	–2.0
Difference	+0.6	+1.2		+0.2	+0.4	

Source: U.S. DHHS: CDC: NCHS: Health United States, 1996-97.

TABLE 4
AGE-ADJUSTED AND EXCESS RATES FOR THE THREE LEADING CAUSES OF DEATH OF AFRICAN AMERICANS AS COMPARED WITH WHITES, BY SEX, IN THE UNITED STATES, 1985 AND 1995

	DEATH RATE PER 100,000 POPULATION		
	AFRICAN AMERICAN	WHITE	EXCESS DEATH RATE[a]
1985			
Males			
1. Heart diseases	310.8	246.2	64.6
2. Malignant neoplasms	239.9	160.4	79.5
3. HIV infection[b]	25.4	8.4	17.0
Females			
1. Heart diseases	188.3	121.7	66.6
2. Malignant neoplasms	131.8	110.5	21.3
3. Cerebrovascular diseases	50.6	27.9	22.7
1995			
Males			
1. Heart diseases	255.9	179.7	76.2
2. Malignant neoplasms	226.8	151.8	75.0
3. HIV infection[b]	84.3	19.6	64.7
Females			
1. Heart diseases	156.3	94.9	61.4
2. Malignant neoplasms	134.1	108.9	25.2
3. Cerebrovascular disease	39.6	23.1	16.5

Source: DHHS: CDC: NCHS: Health United States, 1996-97.

[a] Difference in rates, African Americans compared with whites.

[b] Data for HIV Infection are from 1987.

population when compared with white females. In 1995, the excess death rate was 76.2 per 100,000 population for African American males when compared with white males, and 61.4 per 100,000 population for African American females when compared with white females.

For cancer, the excess death rate in 1985 was 79.5 per 100,000 population for African American males when compared with white males, and 21.3 for African American females when compared with white females. In 1995, the excess death rate for African American males was 75.0 compared with white males, and 25.2 for African American females when compared with white females.

In 1987, the age-adjusted excess death rate for HIV infection was 17.0 per 100,000 population for African American males when compared with white males. However, in 1995, the excess death rate for HIV infection had increased in African American males to 64.7 per 100,000 population. The excess death rates for stroke in 1985 for African American females was 22.7 per 100,000 population when compared with white females. In 1995, however, the excess death rate for stroke declined to 16.5 per 100,000 population.

Years of potential life lost under age 75. As shown in Table 5, in 1985 for heart diseases, African American males lost an average of 38.6 years per 1,000 population before age 75 compared with 23.3 years for white males, an excess of 15.3 years lost per 1,000 population for African American males. African American females lost an average of 19.9 years compared with 8.3 years for white females, an excess of 11.6 years. In 1995, African American males lost an average of 31.5 years of life before age 75 compared with 16.8 years for white males, an excess of 14.7 years. The corresponding values were 16.3 years for African American females compared with 6.5 years for white females, an excess of 9.8 years per 1,000 population.

In 1985, the YPLL before age 75 per 1,000 population due to cancer for African American males was 30.6 years; it was 18.8 years for white males for an excess of 11.8 years (Table 6). Likewise, African American females lost an average 20.2 years before age 75 compared with 15.8 years for white females for an excess of 4.4 years per 1,000 population. Thus, the racial difference in excess YPLL before age 75 was greater between males than between females.

HIV/AIDS in African American males. In 1990, the YPLL before age 75 per 1,000 population for HIV infection was 16.3 years for African American males and 5.4 for white males, an excess of 10.9 years. In 1995, the YPLL had increased to 29.3 years for African American males and to 7.1 years for white males, an excess of 22.2 years (Table 5).

Stroke in African American females. The YPLL before age 75 per 1,000 population from stroke in 1985 for African American females was 5.4, and for white females it was 1.9, an excess of 3.5 years for African American females. In 1995, the YPLL had declined to 4.2 years for African American females and to 1.6 years for white females, an excess of 2.6 years (Table 5).

TABLE 5
YEARS OF POTENTIAL LIFE LOST BEFORE AGE 75 FOR THE LEADING CAUSES OF DEATH FOR AFRICAN AMERICANS AS COMPARED WITH WHITES, BY SEX, IN THE UNITED STATES, 1985 AND 1995

	YEARS LOST PER 1,000 POPULATION UNDER 75 YEARS OF AGE		
	AFRICAN AMERICAN	*WHITE*	*EXCESS YEARS LOST*[a]
1985			
Males			
1. Heart diseases	38.6	23.3	15.3
2. Malignant neoplasms	30.6	18.8	11.8
3. HIV infection[b]	16.3	5.4	10.9
Females			
1. Heart diseases	19.9	8.3	11.6
2. Malignant neoplasms	20.2	15.8	4.4
3. Cerebrovascular diseases	5.4	1.9	3.5
1995			
Males			
1. Heart diseases	31.5	16.8	14.7
2. Malignant neoplasms	26.5	16.5	10.0
3. HIV infection[b]	29.3	7.1	22.2
Females			
1. Heart diseases	16.3	6.5	9.8
2. Malignant neoplasms	19.1	14.3	4.8
3. Cerebrovascular diseases	4.2	1.6	2.6

Source: DHHS: CDC: NCHS: Health United States, 1996-97.

[a] Difference in years lost, African Americans compared with whites.

[b] Data for HIV infection for years of potential life lost are from 1990.

Change in excess deaths and years of potential life lost. For diseases of the heart, the excess age-adjusted death rates between African American males and white males from 1985 to 1995 were compared. The difference in excess death rate for diseases of the heart between African American males and white males increased by 18.0 percent, but decreased by 4.8 percent for African American females and white females (Table 6). Overall, for cancer, the difference in the excess death rates between 1985 and 1995 declined by 5.7 percent between African American males and White males, and increased 13 percent between African American females and white females (Table 6). For HIV Infection, between 1987 and 1995, the age-adjusted excess death rate increased dramatically by 280.6 percent for African American males. These results indicate a widening of the gap between the races for diseases of the heart and for HIV infection, but a narrowing of the gap between males for cancer.

Overall, between 1985 and 1995, the YPLL before age 75 per 1,000 population due to heart diseases for African American males compared with white males decreased by 3.9 percent despite the increase in the excess age-adjusted

TABLE 6
PERCENTAGE CHANGE IN EXCESS DEATH RATES AND YEARS OF POTENTIAL LIFE LOST FOR THE LEADING CAUSES OF DEATH FOR AFRICAN AMERICANS AS COMPARED WITH WHITES, BY SEX, IN THE UNITED STATES BETWEEN 1985 AND 1995

	EXCESS DEATH RATE			*YEARS OF POTENTIAL LIFE LOST*		
	1985	*1995*	*PERCENTAGE CHANGE*	*1985*	*1995*	*PERCENTAGE CHANGE*
Males						
1. Heart diseases	64.6	76.2	18.0[b]	15.3	14.7	3.9[c]
2. Malignant neoplasms	79.5	75.0	5.7[c]	11.8	10.0	15.3[c]
3. HIV infection[a]	17.0	64.7	280.6[b]	10.9	22.2	103.7[b]
Females						
1. Heart diseases	64.5	61.4	4.8[c]	11.6	9.8	15.5[c]
2. Malignant neoplasms	22.3	25.2	13.0[b]	4.4	4.8	9.1[b]
3. Cerebrovascular diseases	20.4	16.5	19.1[c]	3.5	2.6	25.7[c]

[a] Data available from 1987 for excess deaths and 1990 for excess years of potential life lost.
[b] Indicates an increase in the excess death rate between African Americans and whites or the years of potential life lost.
[c] Indicates a decrease in the excess death rate between African Americans and whites or the years of potential life lost.

death rate. For African American females compared with white females, the YPLL decreased by 15.5 percent (Table 6). However, Table 6 also shows that for males, the racial difference in excess YPLL per 1,000 population due to cancer decreased by 15.3 percent. However, the racial difference in excess YPLL due to cancer increased by 9.1 percent, indicating a widening of the gap between the females.

Overall, between 1990 and 1995, the YPLL per 1,000 population due to HIV infection increased strikingly by 103.7 percent for African American males compared with white males. However, the excess YPLL for stroke decreased by 25.7 percent for African American females compared with white females (Table 6).

Discussion

Since the release of the 1985 DHHS *Secretary's Task Force Report on Black and Other Minority Health,*[8] the leading causes of death for African Americans remain major public health problems. Life expectancy for African American males increased only by one-half that of white males between 1985 and 1995. However, the difference in average life expectancy is not as dramatic between females as it is between males. Nevertheless, the disparity in average life expectancy continues to exist. The reasons for the disparity are associated with differential disease burden caused by a host of lifestyle, social, economic, environmental, and genetic factors.

Between 1985 and 1995, the age-adjusted death rate from heart disease, stroke, and cancer have declined for African Americans, which may indicate the impact of multiple interventions, such as the discovery of new and more effective treatment modalities, the adoption of positive lifestyle behaviors, and the implementation of policies to effect economic and environmental changes. Despite the positive trends in age-adjusted death rates for African American males and females, the excess disparity continues to exist. In fact, in some instances, it has increased between the races from 1985 to 1995. For example, the excess age-adjusted death rates for African American males compared with white males increased for both heart disease and HIV infection but decreased for cancer. The excess age-adjusted YPLL for HIV also increased between 1987 and 1995. In addition, the excess death rate and the YPLL for African American females increased for cancer but decreased for heart disease and stroke.

Even though the trends in the age-adjusted death rates have declined, study findings indicate a disturbing increase in the excess age-adjusted heart disease death rate, as well as a dramatic increase in the excess disparity in HIV infection/AIDS deaths between African American and white males. Even though cancer deaths rates have begun to decline, findings also indicate an increase in the excess cancer death rate between African American females and white females. The reasons for the increased excess death rates are not entirely clear, but several studies have found that specific barriers may impede the progress toward closing the racial disparities, but addressing barriers may lead to reducing disparities in health status measures.

Barriers to reducing excess death rates and years of potential life lost. To maintain the current declines in the death rates in general, as well as to address the increasing excess death rates between the races, a multifaceted approach is required. One of the elements of that approach may be a more concerted effort to identify and target barriers to reducing the racial disparities. Studies on CVD and related risk factors,[23,49-67] cancer and associated risk factors,[28-30,68-82] and HIV/AIDS and associated risk factors[37,41,46,83-91] were reviewed to identify barriers to reducing health disparities between African Americans and whites. The studies ranged from randomized control trials to qualitative research using focus groups. The review revealed a variety of barriers that may help to reduce differences in indicators of health status such as life expectancy, excess death rates, and excess YPLL.

Diseases of the heart was the first leading cause of death to show a widening of the gap in excess death rates between African American and white males. The studies reviewed,[23,49-67] however, covered the broader area of CVD and associated risk factors in part to provide a more comprehensive set of barriers. The major CVD risk factors are high blood pressure, high blood cholesterol,

and cigarette smoking. Other factors include obesity and physical inactivity. Reducing disparities for heart disease and associated risk factors requires lifestyle changes as well as pharmacologic therapy to prevent and control major risk factors. Some of the major barriers to reducing or eliminating disparities include inadequate control of blood pressure, poor adherence to medication, cost of medication, lack of health insurance, no social support, and organizational factors that restrict accessibility and availability of services. Even though national education programs such as the National High Blood Pressure Education Program[92] have contributed significantly to the decline in CVD risk factors, continued aggressive efforts may be needed to reduce barriers to eliminating excess heart disease death rates and to stimulating continued declines in YPPL for African Americans in general and African American males in particular. Addressing barriers may require the implementation of large-scale strategies such as those used in tobacco campaigns,[93-94] which combine educational and community mobilization strategies with policy advocacy and regulatory change efforts. In addition, qualitative research on smoking policy change shows that communities have histories, norms, political leaders, and resources that place them in different stages of readiness for change and that the intervention influenced these stages and advanced policy initiatives.[95] Similar interventions should be vigorously maintained for relevant risk factors to reduce the excess death rate and YPPL from heart disease.

The second leading cause of death to show a widening of the gap between the races was cancer. African American females experienced an excess death rate from cancer compared with white females. In general, the cancer death rate among African Americans is 27 percent higher than that for the general population.[96] The simplest, most important preventable risk factor for cancer is cigarette smoking. African Americans have the highest smoking rates of any of the U.S. racial/ethnic groups.[97-100] In addition to smoking, about 72 percent of cancer deaths are due to factors such as alcohol, nutritional and dietary factors, and occupation. Lower SES has also been associated with poorer survival from cancer. Stressors of low SES existence, particularly in inner-city environments, inhibit access to health services while keeping in place behaviors that increase cancer risk.[97] Other factors such as poverty, work and environmental exposures, and living conditions are also associated with increased cancer risk.[98] Several studies[28-30,68-82] have addressed barriers to cancer control, particularly for African Americans. Some of the major barriers include poor knowledge of signs and symptoms, cost of examination, poor perception of cancer risk factors, poor BSE practices, lack of social support, no usual source of care, and no confidence to perform BSE. A concerted approach to eliminate barriers may help to accelerate the decline in the excess cancer death rates and YPLL for African American females.

HIV infection also showed a dramatic widening of the gap in excess deaths for African American males. The HIV infection rate has increased tremendously over the past decade, and it continues to rise. Several studies[37,41,46,83-91] have identified barriers to the reducing the increasing HIV/AIDS epidemic in this country. Some of the major barriers to reducing HIV infection include poor knowledge of HIV transmission methods, unprotected sex with multiple partners, poor perception of HIV risk factors, lack of proper AIDS education and training, and the use of IV drugs.

The dominant ways in which HIV is transmitted in African Americans is through IV drug use, primarily among African Americans at lower income and education levels; homosexual relations; and heterosexual contact.[101] A survey of 900 African American males (thought to be homosexual), conducted by the National Task Force on AIDS Prevention in 1992, found that although 74 percent of the African American males identified themselves as homosexual privately, only 48 percent would do so publicly.[102] Many lived ostensibly heterosexual lives while secretly engaging in sex with males. The result can be deadly for unsuspecting heterosexual partners. This subject continues to be debated in ethical and legal circles.[103] Regrettably, there is no vaccine for HIV infection; however, much research is being conducted to find potential vaccines or drug therapies to arrest the proliferation of HIV infection by preventing or treating the underlying disease process.[104] Thus, many in the African American community will continue to become infected with HIV unless powerful and pragmatic behavioral strategies are implemented to better understand and change high-risk behaviors. In fact, interventions to change high-risk behaviors may be the only means of preventing transmission of HIV.[105] The African American community has been slow to address the realities of HIV/AIDS. Given the high rates of HIV infection in the African American community and its dramatically increasing trend, it is critical to identify factors that may influence the adoption of safe sex practices through AIDS education and prevention.[106]

Even though there is still much to be done to eliminate the disparity in excess deaths in heart disease, cancer, and HIV/AIDS for African Americans, there have been declines in excess cancer death rate for African American males and in excess heart disease and excess stroke death rates for African American females. Favorable trends in CVD risk factors have contributed to the decline in stroke mortality. Improvements in economic and living conditions, effective treatment of hypertension, and reductions in cigarette smoking since the 1960s and in alcohol consumption in the 1980s, as well as better detection and treatment of selected cancers in males, may have contributed to the decline in the excess death rates.

The studies reviewed in this article have presented a variety of barriers to reducing or eliminating differences in the three major health problems for African Americans compared with whites. A major barrier that crosscuts each of the health problems is compliance or adherence. Compliance to medical advice and treatment and engaging in preventive health behaviors are key

issues that have been studied in relationship to several major health problems.[7,52-54,62,72,97,107]

Health researchers, educators, health policy makers, and health planners need to recognize barriers associated with the changing health behavior of African Americans and be willing to develop effective strategies to eliminate these barriers. The Healthy People Objectives for the Nation[108] have already begun to focus discussion on the elimination of disparity among racial and ethnic groups as a priority for the year 2010.

Conclusion

Both the DHHS 1985 Secretary's Task Force report[8] and the Healthy People 2000 report[7] outlined strategies for improving the health status of the African American population. The task force report made recommendations and subsequently funded several intervention activities to help change the attitudes, knowledge, and behavior of African Americans regarding modifiable risk factors. In addition, other federal government agencies including the National Cancer Institute; the National Heart, Lung, and Blood Institute; and the Centers for Disease Control and Prevention funded several prevention studies to improve the health behavior of individuals and communities.

Despite ongoing research efforts, many of the barriers to reducing the disparity in heart disease and HIV infection for African American males and cancer for African American females remain to be eliminated. To significantly reduce the major health problems of African Americans, approaches will be required that address these barriers as well as stimulate health providers, researchers, and health policy formulators to support interventions that are designed strategically to reduce the excess death rates of high-risk population groups. However, health behavior change cannot exclude individual responsibility. Strategies to overcome barriers must empower African Americans of all ages to engage in health promotion and preventive health behaviors rather than living as victims of chance.[109]

This article has outlined three major health problems of African Americans based on the leading cause of deaths, excess death rate, and YPLL. The excess disparity in heart disease and HIV continued to increase over the past 10 years for African American males compared with white males. The excess cancer death rate continued to increase for African American females. To improve the health status and quality of life of African Americans in the future will not only require individuals and communities to implement innovative prevention and education strategies but will also demand system changes that will be responsive to objective-driven and performance-based allocation of health care revenues to eliminate excess health disparities among subgroups of the population that are at high risk of disease. The DHHS has already begun to focus on performance-based outcomes in setting priorities within the Public Health Service based on the Government Performance and Results Act of 1994.[110] This effort along with the Healthy People 2010 Objectives for the Nation[108] will enhance opportunities for the health care delivery system to embrace more prevention-oriented interventions and encourage system changes to address barriers that may impede the reduction of excess health disparities

However, relying on medical interventions alone to improve health status through detecting, treating, and controlling the three major health problems of African Americans has not shown to reduce the excess deaths nor the YPLL over the study period. To reduce premature death and disability in the African American community may not only require major changes in the U.S. health care system but may also require changes in social, economic, and environmental factors characteristic of the inner-city communities where the majority of African Americans reside.

Results from 13 community-wide studies in the United States and abroad suggest that modest population-wide changes in risk behaviors were feasible and may have a dose-response relationship to the intensity of the intervention. Although the study results were not always consistent,[111-113] the general trend suggests that population-based interventions can succeed in meeting some goals of shifting the population to a lower risk. Many segments of the U.S. population have demonstrated substantial risk factor change on their own, but some segments, especially those in certain ethnic groups and of low SES, have not experienced such change.[111,114-116]

Given that the health-seeking behaviors of African Americans vary tremendously depending on age, gender, income, geographic region, insurability, cost, health beliefs, severity of condition, and beliefs about the health care system, interventions to reduce the major health problems need to utilize qualitative approaches to better understand the population before designing interventions. Moreover, developing and implementing preventive health and health promotion interventions for African Americans may require the application of cultural sensitivity and cultural competence. For example, health education activities and programs on changing food preparation practices; lowering fat, salt, and cholesterol in diet; and increasing physical activity done in culturally sensitive settings and incorporating the beliefs and values of the population will enhance the process of changing unhealthy lifestyle behaviors. These strategies must take these factors into consideration before designing the program.

One of the major challenges of the DHHS Secretary's Task Force report[8] was not only to raise awareness about the disparity between African Americans and whites for selected leading causes of death but also to stimulate public health and community action to reduce the disparity. Research and public

health programs designed to reduce death and disability in African American communities have not been successful in closing the gap between African Americans and whites. Thus, the challenge remains to close the health disparity in average life expectancy, deaths rates, and YPLL for the three major health problems of African Americans. The key to health promotion and disease prevention into the 21st century lies in the modification of lifestyles and the establishment of more health-promoting policies and environments.[113] In addition, more culturally based research and evaluation of implementation efforts is recommended to better understand the environmental, lifestyle, and social factors that may place African Americans at higher risk of developing these diseases and to better design cost-effective approaches to promoting health and preventing disease in the African American community using both population-based and high-risk approaches.

APPENDIX
Definitions

Leading cause of death: This is a condition or disease to which most deaths are attributed.

Excess death rate: This is the difference in the death rates between African Americans and whites.

Excess years of potential life lost (YPLL): This is the difference in the YPLL between African Americans and whites.

Major health problem: This is based on three conditions: leading causes of death, excess death rate, and excess YPLL.

Average life expectancy: Life expectancy indicates the chances of survival beyond certain ages if current age-specific mortality rates for an actual population were to continue.

Mortality: This refers to the age-adjusted mortality rates for 1985 and 1995 for heart disease, cancer, stroke, and HIV infection.

Years of potential life loss: The YPLL under age 75 represent the number of years per 1,000 resident population of life lost due to premature death.

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DR. FELDMAN *is Professor Department of Health Education, University of Maryland, 2387 Valley Drive, College Park, Maryland 20742;* MR. FULWOOD *is a doctoral candidate in the Department of Health Education, University of Maryland, 2387 Valley Drive, College Park, MD 20742.*

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RICHARD L. DOUGLASS, MPH, PhD
Professor, Program in Health Administration
328 King Hall
Eastern Michigan University
Ypsilanti, MI 48197

ROBERTO E. TORRES, PhD
Associate Professor, Program in Health Administration
333 King Hall
Eastern Michigan University
Ypsilanti, MI 48197

PAULA SURFUS, MPH
Program in Health Administration
Eastern Michigan University
333 King Hall
Eastern Michigan University
Ypsilanti, MI 48197

BARBARA KRINKE, MHSA
Program in Health Administration
Eastern Michigan University
333 King Hall
Eastern Michigan University
Ypsilanti, MI 48197

LORI DALE, MHSA
Program in Health Administration
Eastern Michigan University
333 King Hall
Eastern Michigan University
Ypsilanti, MI 48197

CULTURALLY COMPETENT PROFESSIONALS IN THERAPEUTIC ALLIANCES ENHANCE PATIENT COMPLIANCE

NIELI LANGER, PhD
University of the Incarnate Word

Abstract: Medical training has traditionally focused on diagnosis and treatment of disease, with the notion that if these two factors are satisfactorily managed, the desired outcome will inevitably follow. When it does not, failure is often blamed on patient noncompliance. Failure of patients to return for follow-up visits or comply with medication regimens has been shown to be a major barrier to the delivery of effective medical care. However, effective clinical decision making requires that physicians skillfully address not only the biomedical aspects of diseases and their management, but also the sociobehavorial characteristics of patients. The authors maintain that patient participation is necessary for compliance and that a naturally occurring therapeutic alliance between physician and patient incorporates factors such as lifestyle, family, and living circumstances and an awareness of the culturally unique needs of minority patients. Integration of these factors into professional decision making and practical management plans will enhance patient compliance.

Key words: Therapeutic alliance, cultural competence, patient-physician communication, minority populations, patient empowerment.

Patient compliance has become one of the main factors for successful medical intervention. Compliance is the willingness or ability to perform in a prescribed manner. It is the extent to which a patient's health behavior follows medical advice. The term includes three aspects of patient behavior: appointment-keeping, medication compliance, and adherence to a general medical protocol for good health. The spectrum of health behavior ranges between dropouts, noncompliers, compliers, overcompliers, and abusers.[1]

The word *compliance* has overtones of doing as one is told or obeying orders. It assumes that care providers, because of their training and expertise, know what is best for patients and that patients have an obligation to follow the advice once given. The importance of noncompliance for medical practice is

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obvious: the therapeutic goal is not achieved in these patients, the results of therapeutic trials may be influenced, and the cost of medications prescribed but not taken is enormous.[2]

While more than 200 patient variables have been investigated, few diseases, demographic conditions, psychosocial factors, or treatment protocols consistently predict for noncompliance.[3] Fineman[4] investigated noncompliance in a cross-cultural multiservice center as it was defined by the interdisciplinary team composed of physicians, nurses, and social workers. He found their collective definition of noncompliance to be socially constructed and subjectively defined and interpreted. Care providers defined behavior as compliant when it was patterned by their expectations and noncompliant when behavior deviated from their expectations. The team members expected health-appropriate behavior but also indicated that clients should be "honest, punctual, cooperative, reasonable, responsible, self-aware, self-interested, polite, open-minded, and supportive of staff's efforts." In the nursing literature, there is abundant confirmation that minority patients are frequently labeled "difficult" or "problem" patients.[5-6]

Health care providers have a long way to go before feeling comfortable when patients exercise autonomy, despite the existence of a long tradition of contending with patients who do, dating back at least as far as Hippocrates, who wrote, "Keep a watch also on the faults of the patients, which often make them lie about the taking of things prescribed." Therefore, even if research studies have established that a particular treatment is of proven value, individuals may decide that for them the costs are excessive and too high a price to pay for the potential benefit. The costs, of course, are measured in emotional, psychological, and social terms as well as physical and financial ones.

Health professionals judge regimens on their medical worth, but patients judge regimens on social priorities. For this reason, failure of the health professional to recognize the patient's perspective occurs when the health care provider claims to have professional authority. How the patient perceives the ailment determines whether she will comply. The patient understands the regimen in terms of the way it will affect her life. The health professional understands the protocol in terms of the way it will affect the patient's health. However, to enhance compliance, reorientation of the medical perspective is necessary.

Despite increased awareness of the need for a multicultural approach to health care delivery, minority populations continue to be treated by care providers and institutions that often disregard or are insensitive to patients' cultural norms and their impact on service consumption. Lack of awareness of cultural issues increases social distance, breaks down communications, and precipitates misconceptions between minority patients and their health care providers. Therefore, opportunities for patient dissatisfaction and noncompliance increase. This article suggests that attitudinal and practical means to strengthen the therapeutic alliance between care provider and patient, with the recognition of the care provider's need to develop cultural competency, is the thoughtful application of cultural data to practice. The relationship that recognizes the patient's individual lifestyle and the adaptation of treatment plans and services that meet culturally unique needs is critical to determining the likelihood of patients engaging in self-care activities and compliance.[7]

Care from the patient's perspective

Regardless of demographics or ethnically defined health care practices, the foundation for patient care is the patient's definition of the problem.[8] Several studies have demonstrated that the extent to which patients are able to express themselves fully about their illnesses correlates significantly with physiological health outcomes, such as blood pressure control and resolution of headaches.[9-10] Therefore, establishing a working relationship with the patient is the prerequisite to fostering compliance. Brock and Salinsky[11] use the term "therapeutic alliance" to denote a process in which the health care provider communicates an assessment of the patient's problem and coordinates a practical management plan that is conducive to patient compliance. This assessment must consider and integrate information about all the systems in which the person exists: biological, psychological, informal/formal social support, and cultural. This concept of "whole person care" then allows the care provider to tailor treatment recommendations to reflect the patient's goals and expectations regarding health and health care as well as her beliefs, values, and life circumstances. Elevating the patient's status within the therapeutic alliance increases the likelihood of her participation, that is, enhanced compliance.

Interviews with successful patients attribute their progress to trust they felt toward the care provider, being understood by the care provider, and the feeling of independence in making choices.[12] In the literature on both helping relationships and administrative skills attributed to successful leaders, the attribute "trust" appears to be the primary component. According to Rosen and Brown, "Trust is the glue that holds the relationship together."[13]

Trust implies the ability to listen, hear, and respond. It does not imply that the care provider be rigidly consistent but that he or she be dependable. This trust engenders a voluntary, cooperative environment that provides freedom of choice for the patient. This environment also fosters professional/patient recognition that the patient is empowered to prioritize what is important to her and with professional guidance will make better, more informed choices.

Empathy is the ability to understand where the patient is coming from. Empathic listening skills give the patient the space in which to explore her feelings, vent emotions, and feel understood without being judged. A relationship characterized by empathy, respect, and reality is the foundation for positive change. The patient may experience and understand aspects of herself that she may have previously repressed. The patient will be able to cope with the problems of the disorder more adequately and with a greater degree of comfort.

Cultural sensitivity in patient care

Managing a therapeutic alliance that also involves cultural diversity means developing awareness, sensitivity, knowledge, and skills that encourage interaction that is enhanced rather than hindered by differences. The health care provider can be a catalyst in providing acceptable and appropriate health care in situations that involve diversity, with awareness and sensitivity to communication and psychosocial skills as well as flexibility.

The lack of awareness of the culturally unique needs of minority patients increases social distance and precipitates misconceptions between minority clients and their care providers. To address the needs of minority patients, health care providers will need to develop culturally competent service delivery—that is, they must be familiar with the subculture of the people they serve and with their social conditions and needs. The care provider needs to learn to listen to the music, not just the words.

The Covey Leadership Center asserts, "But while all of these skills are important, attitude is even more important. . . . To work effectively, skills must be built on a caring attitude and a sincere desire to understand."[14] When professionals convey a superior attitude or are pessimistic about the populations they serve, these attitudes are conveyed in subtle ways, including body language, tone of voice, and choice of words. These verbal and nonverbal cues may communicate health messages that are interpreted as inappropriate, irrelevant, or patronizing. Multicultural health care requires a willingness on the part of care providers to examine how their values, feelings, and attitudes can affect the therapeutic relationship. Those who do so become aware of the potential differences in the values of culture and of the necessity to explore those differences with their patients. Care providers and patients alike need to remember that one can choose an attitude.

Cardinas explains, "While culture may not always play a crucial role in the treatment of emergencies and acute conditions, cultural dynamics shape the process and outcomes of interventions designed to promote self-care behaviors."[15] Culture is relevant to the management of a chronic disease such as diabetes because of the disease's lifelong course and constant focus on culturally embedded behaviors. Identifying barriers to health promotion may help practitioners understand why recommended health regimens sometimes do not occur. These barriers create competing priorities such as poverty, substandard and overcrowded housing, neighborhood crime, lack of resources such as transportation, child care, and so on, as well as lack of knowledge and skills.

Disproportionately high rates of diabetes exist within the African American (7 percent), Hispanic American (10 percent), and Native American (35 percent) communities.[16] Many racial and ethnic populations known to suffer disproportionately from the burden of diabetes face stresses and challenges to basic survival that displace diabetes self-care and other long-term health conditions. For the individual, the demands of daily survival for oneself and one's family almost always will be a higher priority.

The therapeutic alliance approach in diabetes care maintains that persons have the right to make informed decisions about their own care. They can be prepared for the role of self-directed care by learning about diabetes and its care and by exploring with the health care provider their own health-related values, needs, goals, and aspirations regarding diabetes care.[17] The routine use of self-monitoring of capillary blood glucose by diabetic patients currently provides the basis for both clinical management and ongoing investigation. The use of glucose reflectance meters with a memory microchip capable of storing hundreds of consecutive blood glucose determinations has been used to ensure that glucose data are reliable and accurately reported by patients.

The present author collaborated in a study[18] of cultural diversity and adherence to a gestational diabetes protocol (diabetes in pregnancy) with two diverse groups of women from New York and Texas. The Hispanic American group from San Antonio, Texas, and the African American group from the Bronx, New York, performed self-monitoring of blood glucose from diagnosis until delivery, with both groups recording blood glucose results daily in their logbooks.

The two groups were compared on several performance measures, such as total number of testings, clinic attendance, and level of glycemic control achieved. There were no significant differences in the performance measures between these two groups at diverse geographic locations. Stratification by ethnic origin revealed no effect on performance and compliance in ambulatory self-monitoring of blood glucose. The reporting performance of all the participating subjects resulted in an actual compliance rate of 60 to 70 percent of testings required of the patients. This was consistent with other researchers[19] who found that race or ethnicity as a predictor of enduring or successful treatment participation is not a significant factor.

An interdisciplinary team worked directly with the medical team in creating a biopsychosocial training model that concentrated on delivery of constructive, nonaggressive criticism and encouragement of active coping by the patient, including the viewing of noncompliance as a temporary rather than permanent lapse. The findings suggest that this approach enhanced positive interaction between patient and health care team and may have contributed to diabetic regimen compliance regardless of socioeconomic level or ethnic diversity between care providers and care recipients.

In another study, we compared the emotional profile of pregnant Mexican American women with preexisting diabetes to nondiabetic controls.[20] For women with preexisting diabetes, the diabetic control regimen becomes part of their lives since they cannot assume a cure. The severity of the disease was associated with decreased compliance as measured by the rate of clinic visits and no-shows. Furthermore, there was overall decreased compliance in the diabetic group when compared with the nondiabetic subjects.

Gestational diabetic women are struggling with an acute disease that will be resolved with the birth of the fetus, while preexisting diabetic patients have a lifetime of diabetes-related crises for which they may have developed

specific coping mechanisms. Chronically ill patients are often unable or unwilling to achieve established goals due to physical, social, or psychological limitations. The patient comprehends the protocol in terms of the way it will affect her life and complies accordingly.

Thus, the interdisciplinary team, instead of criticizing the patient for failure to comply, provided a backdrop of acceptance and support by listening and acknowledging the patient's social and cultural background. Mutual exchange of information can lead to negotiation and facilitation of interaction leading to adaptation of a regimen that is most likely to result in compliance. The physician who assesses both the medical and psychosocial forces that influence preexisting diabetes will be in the strongest position to enhance medical outcome and personal adaptation. As human beings, patients have the right to make the major decisions about their lives, including decisions about management of a disease. When working in partnership, the health care provider helps the patient make informed choices for herself about self-care. Because the disease and the person with the disease cannot be separated, it follows that psychological care and physical care cannot be separated either. Together, they comprise whole person care.

Research evidence supports the clinical experience of health care providers that there are close links between psychological adjustment and disease control. Almost certainly the relationship works in both directions: the quality of control affects psychological adjustment, and psychological adjustment affects control.[21] As health care providers, we need to concentrate more on the person and not the disease. We can help patients cope with disease by increasing patients' feelings of competence in their ability to manage their disorders. Building on the foundation of a therapeutic alliance and culturally competent provision of care, we can enhance patient performance and compliance. The bonds of shared humanity—of trust, mutual respect, and concern—are the rewards of interaction between care provider and care recipient. A "checklist of empowerment for compliance skills," including those listed below, provides a useful evaluation tool for all professionals in health care services:[22]

- **Respect**. The health care provider has been schooled to expect respect from patients. To create a meaningful therapeutic alliance, the professional must also develop the ability to express respect for the patient.
- **Tolerating ambiguity**. The health care provider needs to learn to react appropriately to new, different, and/or unpredictable situations arising from attention to the patient's values. Empowering for compliance implies an understanding of value and social preferences that helps the professional support patient self-determination.
- **Being nonjudgmental**. The health care provider needs to learn to recognize that his or her prescribed regimen is seldom the only way to provide effective care. Empowerment for compliance functions with an acceptance of a patient's value and social location and adapts service delivery to accommodate the context within which the patient functions. A care provider may recommend self-monitoring blood glucose, multiple testings daily, and exercise for a diabetic patient. However, the physician also needs to be aware of the patient's financial ability to pay for this equipment and if the patient's lifestyle can accommodate an exercise regimen.
- **Understanding the role played by one's own expectations**. Perhaps the first and most important step in creating the foundation for empowerment for compliance lies in an examination by the health care provider of his or her own expectations and an understanding of the role these expectations play in an alliance between the provider and the patient. Unfulfilled expectations on the part of the health care provider can lead to labeling the client as noncompliant and her behavior as inappropriate and unreasonable, when, in reality, the behavior demonstrated may be completely acceptable in the patient's sociocultural location. Labeling a patient as uncooperative or noncompliant as a result of the health care provider's unfulfilled expectations can destroy the trust and respect necessary for effective interaction.

This article suggests strategies for establishing and sustaining relationships between care provider and patient. The most important strategy requires a reevaluation of health care professionals' attitudes toward patients' culturally defined behavior. Customizing health and behavior recommendations for each patient with the recognition that one size does not fit all is a major step toward patient satisfaction and compliance as well as whole person, patient-centered care.

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DR. LANGER *is Associate Professor of Social Gerontology, University of the Incarnate Word, 4301 Broadway, San Antonio, TX 78209.*

PHYSICIAN PERCEPTIONS OF BARRIERS TO CARE FOR INNER-CITY LATINO CHILDREN WITH ASTHMA

MARIELENA LARA, MD, MPH
FELICIA ALLEN, MPH
LINDA LANGE, DrPH
University of California, Los Angeles and RAND Health

Abstract: This article describes physician perspectives on barriers to quality primary care experienced by inner-city children with asthma and presents policy recommendations to reduce these barriers. The authors interviewed 30 physicians who take care of children with asthma in an inner-city Latino neighborhood, conducted a qualitative analysis of interview themes, and used a consensus group method to recommend policy actions. Inner-city physicians described significant access, quality of care, and other barriers in providing state-of-the-art primary care for asthma. Physicians recommended that eliminating financial barriers to care, including lack of health insurance and/or comprehensive health coverage for necessary medications and equipment, is the most important required policy action. In addition, inner-city physicians recommended that medical care and public health programs provide bilingual education for children with asthma and their families and train primary care physicians about how to provide effective asthma care to children with asthma in the inner city.

Key words: Asthma, child, health care accessibility, quality of health care, Latino/Hispanic Americans, qualitative methods, health policy, health services, asthma therapy, poverty.

Asthma is an important public health problem for Latino and non-Latino children in the United States. In 1990, 13 percent of all children younger than 15 years of age in the continental United States and Puerto Rico were of Latino origin. An estimated one-half million of these children had asthma symptoms; about two-thirds of those affected were of Puerto Rican origin and about one-third of Mexican and other Latino origin.[1-4] In highly Latino populated states such as California, there will be more Latino than non-Latino

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ARTHUR M. FOURNIER, MD
Associate Dean for Community Health Affairs
Department of Family Medicine
University of Miami School of Medicine
P.O. Box 016700
Miami, FL 33101

CULTURAL HUMILITY VERSUS CULTURAL COMPETENCE: A CRITICAL DISTINCTION IN DEFINING PHYSICIAN TRAINING OUTCOMES IN MULTICULTURAL EDUCATION

MELANIE TERVALON, MD, MPH
Children's Hospital Oakland
JANN MURRAY-GARCÍA, MD, MPH
University of California, San Francisco

Abstract: Researchers and program developers in medical education presently face the challenge of implementing and evaluating curricula that teach medical students and house staff how to effectively and respectfully deliver health care to the increasingly diverse populations of the United States. Inherent in this challenge is clearly defining educational and training outcomes consistent with this imperative. The traditional notion of competence in clinical training as a detached mastery of a theoretically finite body of knowledge may not be appropriate for this area of physician education. Cultural humility is proposed as a more suitable goal in multicultural medical education. Cultural humility incorporates a lifelong commitment to self-evaluation and self-critique, to redressing the power imbalances in the patient-physician dynamic, and to developing mutually beneficial and nonpaternalistic clinical and advocacy partnerships with communities on behalf of individuals and defined populations.

Key words: Medical education, minority populations, multicultural, racism, underserved populations.

The increasing cultural, racial, and ethnic diversity of the United States compels medical educators to train physicians who will skillfully and respectfully negotiate the implications of this diversity in their clinical practice. Simultaneously, increasing attention is being paid to nonfinancial barriers that operate at the level of the physician/patient dynamic. This dynamic is often compromised by various sociocultural mismatches between patients and providers, including providers' lack of knowledge regarding patients'

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health beliefs and life experiences, and providers' unintentional and intentional processes of racism, classism, homophobia, and sexism.[1-3]

Several recent national mandates calling for innovative approaches to multicultural training of physicians have emerged from various sources. The Pew Health Professions Commission, specifically seeking to give direction to health professions education for the twenty-first century, stated that "cultural sensitivity must be a part of the educational experiences that touches the life of every student."[4] The Institute of Medicine defines *optimal primary care* as including "an understanding of the cultural, nutritional and belief systems of patients and communities that may assist or hinder effective health care delivery."[5]

The necessity for multicultural medical education provides researchers and program developers with the challenge of defining and measuring training outcomes and proving that chosen instructional strategies do indeed produce these outcomes. However, in the laudable urgency to implement and evaluate programs that aim to produce cultural competence, one dimension to be avoided is the pitfall of narrowly defining competence in medical training and practice in its traditional sense: an easily demonstrable mastery of a finite body of knowledge, an endpoint evidenced largely by comparative quantitative assessments (i.e., MCATs, pre- and postexams, board certification exams).

Rather, cultural competence in clinical practice is best defined not by a discrete endpoint but as a commitment and active engagement in a lifelong process that individuals enter into on an ongoing basis with patients, communities, colleagues, and with themselves (L. Brown, MPH, Oakland health advocate, personal communication, March 18, 1994). This training outcome, perhaps better described as cultural humility versus cultural competence, actually dovetails several educational initiatives in U.S. physician workforce training as we approach the twenty-first century.[4-7] It is a process that requires humility as individuals continually engage in self-reflection and self-critique as lifelong learners and reflective practitioners.[1,2,7] It is a process that requires humility in how physicians bring into check the power imbalances that exist in the dynamics of physician-patient communication by using patient-focused interviewing and care.[8,9] And it is a process that requires humility to develop and maintain mutually respectful and dynamic partnerships with communities on behalf of individual patients and communities in the context of community-based clinical and advocacy training models.[4,6,7]

Self-reflection and the Lifelong Learner Model

Increasing trainees' knowledge of health beliefs and practices is critically important. For instance, the Cambodian child who comes in with the linear marks of "coining," a Southeast Asian healing practice, should not be mistaken for the victim of parental child abuse.

To be avoided, however, is the false sense of security in one's training evidenced by the following actual case from our experience: An African American nurse is caring for a middle-aged Latina woman several hours after the patient had undergone surgery. A Latino physician on a consult service approached the bedside and, noting the moaning patient, commented to the nurse that the patient appeared to be in a great deal of postoperative pain. The nurse summarily dismissed his perception, informing him that she took a course in nursing school in cross-cultural medicine and "knew" that Hispanic patients overexpress "the pain they are feeling." The Latino physician had a difficult time influencing the perspective of this nurse, who focused on her self-proclaimed cultural expertise.

This nurse's notion of her own expertise actually stereotyped the patient's experience, ignored clues (the moaning) to the patient's present reality, and disregarded the potential resource of a colleague who might (albeit not necessarily) be able to contribute some relevant cultural insight. The equating of cultural competence with simply having completed a past series of training sessions is an inadequate and potentially harmful model of professional development, as evidenced by this case.

In no way are we discounting the value of knowing as much as possible about the health care practices of the communities we serve. Rather, it is imperative that there be a simultaneous process of self-reflection (realistic and ongoing self-appraisal) and commitment to a lifelong learning process. In this way, trainees are ideally flexible and humble enough to let go of the false sense of security that stereotyping brings. They are flexible and humble enough to assess anew the cultural dimensions of the experiences of each patient. And finally, they are flexible and humble enough *to say that they do not know when they truly do not know* and to search for and access resources that might enhance immeasurably the care of the patient as well as their future clinical practice.

In a related manner, an isolated increase in knowledge without a consequent change in attitude and behavior is of questionable value. In fact, existing literature documenting a lack of cultural competence in clinical practice most reflects not a lack of knowledge but rather the need for a change in practitioners' self-awareness and a change in their attitudes toward diverse patients.[10-13] These data indicate that the prescription of clinical resources from prevention services to potentially life-saving procedures is often differential, dependent on the race or ethnicity of the patient. For example, a study in a university emergency department showed that Latinos were half as likely as white patients to receive analgesia for the same, usually very painful, long-bone fractures, regardless of the linguistic capability or insurance status of the patient.[10] A follow-up study in the same institution showed no difference in physicians' assessment of the level of pain experienced by white and Latino patients experiencing the same, isolated injury.[11] Another study showed that while African Americans are twice as likely to go blind from progressive ophthalmologic diseases such as glaucoma, they are half as likely to receive sight-saving procedures.[12] Such disturbing evidence[13] from the medical profession is a sobering reflection of the parallel reality and tragic costs of racism that persist in American society and that potentially influence every physician.

Clearly, program developers and researchers cannot, in our cultural competency training, simply stimulate a detached, intellectual practice of describing "the other" in the tradition of descriptive medical anthropology. At the heart of this education process should be the provision of intellectual and practical leadership that engages physician trainees in an ongoing, courageous, and honest process of self-critique and self-awareness. Guiding trainees to identify and examine their own patterns of unintentional and intentional racism, classism, and homophobia is essential.[1,2,14]

One way to initiate such a constructive process is to have trainees think consciously about their own, often ill-defined and multidimensional cultural identities and backgrounds.[2] In leading trainees into this process of cultivating self-awareness and awareness of the perspectives of others, trainers and program planners have used the following pedagogical approaches with success: small-group discussions; personal journals; availability of constructive professional role models from cultural groups and from the trainee's groups; and videotaping and feedback, including directed introspection of residents' interactions with patients.[1-3,15,16] Recognition and respect for others' cultural priorities and practices is facilitated by such initial and ongoing processes that engender self-knowledge.

At the same time and by the same process of self-reflection, awakening trainees to the incredible position of power physicians potentially hold over all patients, particularly the poor, is critical.[2,9,17] Especially in the context of race, ethnicity, class, linguistic capability, and sexual orientation, physicians must be taught to repeatedly identify and remedy the inappropriate exploitation of this power imbalance in the establishment of treatment priorities and health promotion activities.

Again, humility, and not so much the discrete mastery traditionally implied by the static notion of competence, captures most accurately what researchers need to model and hold programs accountable for evaluating in trainees under the broad scope of multicultural training in medical education.

Patient-focused interviewing and care

Embodied in the physician who practices cultural humility is the patient-focused or language-focused interviewing process.[8,9,18,19] Studies of patient-physician communication have shown a strong bias on the part of physicians against patient-initiated questions and agendas, with physicians in one study initiating over 90 percent of the questions.[19,20] Another study[21] demonstrated that although poor and minority patients wanted as much information regarding their conditions as did other patients, they received less information regarding their conditions, less positive or reinforcing speech, and less talk overall.[9, 21]

Patient-focused interviewing uses a less controlling, less authoritative style that signals to the patient that the practitioner values what the patient's agenda and perspectives are, both biomedical and nonbiomedical. With these communication skills, perhaps along with other specifically cross-cultural interaction techniques,[3,22,23] physicians potentially create an atmosphere that enables and does not obstruct the patient's telling of his or her own illness or wellness story. This eliminates the need for a complete mastery of every group's health beliefs and other concerns because the patient in the ideal scenario is encouraged to communicate how little or how much culture has to do with that particular clinical encounter.

For example, Ridley[14] describes the uniqueness of a patient by detailing the patient's "conjoint membership in eight cultural roles:" as a Mexican American, male, father, husband, Catholic, mechanic, night-school student, and resident of East Los Angeles. Only the patient is uniquely qualified to help the physician understand the intersection of race, ethnicity, religion, class, and so on in forming his (the patient's) identity and to clarify the relevance and impact of this intersection on the present illness or wellness experience. Relevant and effective prevention, health promotion, and therapeutic strategies can then be developed that take into account the patient's life priorities, health beliefs, and life stressors. Humility is a prerequisite in this process, as the physician relinquishes the role of *expert* to the patient, becoming the *student* of the patient with a conviction and explicit expression of the patient's potential to be a capable and full partner in the therapeutic alliance.

Community-based care and advocacy

There is increasing consensus that a substantial portion of physicians' clinical training needs to occur in community sites.[4,6,24-26] It is argued that training needs to happen in arenas where most physicians will eventually practice, away from the university-based, largely tertiary medical center. Part of this training directive includes a population-based approach to health promotion and disease prevention that works toward the optimal health of communities; that is, health in its broadest sense of physical, mental, and social well-being. Evans[24] states that "surely a small part of each physician's responsibility should extend beyond the care of individual patients to the advocacy for changes in the community's policies and practices that influence determinants of health, causes of disease, and the effectiveness of health services."

Competency in advocacy is actually mandated by the American Academy of Pediatrics as a skill to be acquired during pediatric residency. This professional skill is to be taught by way of "structured educational experiences that prepare residents for their future role as advocates for the health of all children . . . with particular attention to underserved populations."[6]

It is hoped that community-based care and advocacy training would go beyond working with community physicians and even beyond training in legislative advocacy to include systematically and methodically immersing trainees in mutually beneficial, nonpaternalistic, and respectful working relationships with community members and organizations. Experiencing with the community the factors at play in defining health priorities, research

activities, and community-informed advocacy activities requires that the physician trainee recognize that foci of expertise with regard to health can indeed reside outside of the academic medical center and even outside of the practice of Western medicine. Competence, thus, again becomes best illustrated by humility, as physician trainees learn to identify, believe in, and build on the assets and adaptive strengths of communities and their often disenfranchised members. Requiring ongoing self-reflection and a parallel notion of patient- (community-) focused interactions, the possibility then exists for planning, practice, and advocacy in community health work in which physicians and physician trainees are both effective students of and partners with the community.

Institutional consistency

The same processes expected to affect change in physician trainees should simultaneously exist in the institutions whose agenda is to develop cultural competence through educational programs. Self-reflection and self-critique at the institutional level is required, encompassing honest, thorough, and ongoing responses to the following questions: What is the demographic profile of the faculty? Is the faculty composition inclusive of members from diverse cultural, racial, ethnic, and sexual orientation backgrounds? Are faculty members required to undergo multicultural training as are the youngest students of the profession? Does the institutional ethos support inclusion and respectful, substantive discussions of the clinical implications of difference? What institutional processes contradict or obstruct the lessons taught and learned in a multicultural curriculum (i.e., if it is taught that practitioners should not use children or other family members as translators, does the institution provide an accessible alternative?)? What is the history of the health care institution with the surrounding community? And what present model of relationship between the institution and the community is seen by trainees?

Time-limited and explicit educational goals are one dimension of demonstrated institutional cultural competence. For instance, developing a written plan of faculty recruitment and/or curricular development to be in place by a designated date could be a point to which the community and/or other external entities hold the institution publicly accountable with regard to issues of race, ethnicity, language, culture, sexual orientation, and class in health care.

Summary of the challenge to medical education researchers

The emphasis on demonstration of process as opposed to endpoint is not meant to imply that training outcomes in cultural competence programs cannot be measured or monitored. Capturing the characteristic of cultural humility in individuals and institutions is possible, especially with mixed methodologies that use qualitative methods (including participant observation, key informant interviews, trainees' journals, and mechanisms for community feedback)[27-30] and action research models[31,32] to complement traditional quantitative assessments (pre- and postknowledge tests, patient and trainee surveys)[27-30] of program effectiveness. A potentially valuable measure is the documentation of an active, ongoing institutional process that includes training, established recruitment and retention processes, identifiable and funded personnel to facilitate the meeting of program goals, and dynamic feedback loops between the institution and its employees and between the institution and patients and/or other members from the surrounding community.

This is not to say that the measurement of individuals' or institutions' cultural competence is a well-developed area of research. Witness this present discussion on defining training outcomes. Indeed, the definition and measurement of program effectiveness in producing cultural competence is a relatively new arena of inquiry in need of careful and attentive intellectual leadership. Nonetheless, acknowledging the necessity for creativity in a program's development and evaluation stages will help avoid the pitfall of adopting the status quo in documenting clinical competence.

Conclusion

In this critically important dialogue of defining training outcomes, it is proposed that the notion of cultural humility be distinguished from that of cultural competence. Cultural humility incorporates a lifelong commitment to self-evaluation and critique, to redressing the power imbalances in the physician-patient dynamic, and to developing mutually beneficial and nonpaternalistic partnerships with communities on behalf of individuals and defined populations.

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DR. TERVALON is currently Senior Director, Office of the President at The California Endowment, 21650 Oxnard Street, Suite 1200, Woodland Hills, CA 91367, and former Director of the Multicultural Curriculum Program (MCCP) at Children's Hospital, Oakland, California. DR. MURRAY-GARCÍA is a former Fellow at the Institute for Health Policy Studies at the University of California, San Francisco, and the former Research Associate with the MCCP.

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Policy Brief 1

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Rationale for Cultural Competence in Primary Health Care

Nationally, health care organizations and programs are struggling with the challenges and opportunities to respond effectively to the needs of individuals and families from racially, ethnically, culturally and linguistically diverse groups. The incorporation of culturally competent approaches within primary health care systems remains a great challenge for many states and communities. Numerous reasons justify the need for cultural competence in health care at patient-provider level. These include but are not limited to the following:

- the perception of illness and disease and their causes varies by culture;
- diverse belief systems exist related to health, healing and wellness;
- culture influences help seeking behaviors and attitudes toward health care providers;
- individual preferences affect traditional and non-traditional approaches to health care;
- patients must overcome personal experiences of biases within health care systems; and
- health care providers from culturally and linguistically diverse groups are under-represented in the current service delivery system.

These patient-provider issues substantiate the need for primary health care organizations to develop policies, structures, practices and procedures to support the delivery of culturally and linguistically competent services. The rationale to incorporate cultural competence into organizational policy are numerous. The National Center for Cultural Competence has identified six salient reasons for review in this policy brief.

Why is there a compelling need for cultural competence?

■ *To respond to current and projected demographic changes in the United States.*
The make-up of the American population is changing as a result of immigration patterns and significant increases among racially, ethnically, culturally and linguistically diverse populations already residing in the United States. Health care organizations and programs, and federal, state and local governments must implement systemic change in order to meet the health needs of this diverse population. Data from the 1990 census reveal that the number of persons who speak a language other than English at home rose by 43 percent to 28.3 million. Of these, nearly 45 percent indicate they have trouble speaking English. The results of a March 1997 survey conducted by the Census Bureau reveal that one in every ten persons in the United States is foreign-born. Currently, the US foreign-born population comprises a larger segment than at any time in the past five decades. This trend is expected to continue. The Children's Defense Fund predicts that early in the first decade following the year 2000, there will be 5.5 million more Latino children, 2.6 million more African-American children, 1.5 million more children of other races and 6.2 million fewer white, non-Latino children in the United States.

■ *To eliminate long-standing disparities in the health status of people of diverse racial, ethnic and cultural backgrounds.*
Nowhere are the divisions of race, ethnicity and culture more sharply drawn that in the health of the people in the United States. Despite recent progress in overall national health, there are continuing disparities in the incidence of illness and death among African Americans, Latino/Hispanic Americans, Native Americans, Asian Americans, Alaskan Natives and Pacific Islanders as compared with the US population as a whole. In recognition of these continuing disparities, the President of the United States has targeted six areas of health status and committed resources to address cancer, cardiovascular disease, infant mortality, diabetes, HIV/AIDS and child and adult immunizations aggressively.

Cancer. Research shows, in general, that people of diverse racial, ethnic and cultural heritage are less likely to get regular medical checkups, receive

U.S. Department of Health & Human Services
Public Health Service
HRSA
Health Resources & Services Administration
BPHC
Bureau of Primary Health Care
MCHB

immunizations, and be routinely tested for cancer, when compared with the majority U.S. population.

- Cancer deaths are disproportionately high among Latino/Hispanic Americans and African Americans.
- Vietnamese women are five times more likely to have cervical cancer and Chinese Americans five times as likely to have liver cancer.

Cardiovascular disease. Disparities exist in the prevalence of risk factors for cardiovascular disease (coronary heart disease and stroke). Racial and ethnic groups have higher rates of hypertension, tend to develop hypertension at an earlier age and are less likely to undergo treatment to control their high blood pressure.

- Mexican-American men and women have elevated blood pressure rates.
- Obesity continues to be higher for African American and Mexican-American women.
- Only 50 percent of Native Americans, 44 percent of Asian Americans and 38 percent of Mexican Americans have had their cholesterol checked within the past two years.
- Coronary heart disease mortality is higher for African Americans
- Stroke is the only leading cause of death for which mortality is higher for Asian-American males.

Infant mortality. Current studies document that despite recent advances, African American and Native American babies still die at a rate that is two to three times higher than the rate for white American babies.

- Statistics reveal that among Native Americans and Alaskan Natives, the incidence of Sudden Infant Death Syndrome (SIDS) is more than three to four times the rate for white American babies.
- While the overall infant mortality rate has declined, the gap between black and white infant mortality rates has widened.

Diabetes. Studies indicate that diabetes is the seventh leading cause of death in the United States. Approximately 16 million people in the US have diabetes.

- African Americans are 1.7 times more likely, Latino/Hispanic Americans are 2.0 times more likely, and Alaskan Natives and Native Americans are 2.8 times more likely to have diabetes than whites.
- The Pima Tribe of Arizona has the highest known prevalence of diabetes of any population in the world.
- Native Americans and African Americans have higher rates of diabetes related complications such as kidney disease and amputation as compared to the total population.

HIV/AIDS. Recent data from prevalence surveys and from HIV/AIDS case surveillance continue to reflect the disproportionate impact of the epidemic on racially, ethnically and linguistically diverse groups, especially women, youth and children.

- African Americans and Hispanic/Latino groups accounted for 47 and 20 percent, respectively, of persons diagnosed with AIDS in 1997.
- Among African Americans, 56 percent of new HIV infections and AIDS cases are a result of intravenous drug usage; for Hispanic/Latino groups, 20 percent of new HIV infections and AIDS cases result from intravenous drug use.
- Seventy-five percent of HIV/AIDS cases reported among women and children occur among diverse racial and ethnic groups.

Child and Adult Immunizations. Statistics from *the Presidents's Initiative on Race* reveal that for the most critical childhood vaccines, vaccination levels for preschool children of all racial and ethnic groups are about the same. However, immunization levels for school age children and elder adults of diverse racial and ethnic backgrounds continue to lag when compared to the overall vaccination rates of the general U.S. population.

- While 79 percent of white preschoolers are fully immunized by two years of age, only 74 percent of African American and 71 percent of Hispanic/Latino children, including preschoolers and school-aged children, are fully vaccinated against childhood diseases.
- Annually approximately 45,000 adults die of infections related to influenza, pneumococcal infections and hepatitis B despite the availability of preventive vaccines.
- Among the elderly, there is a disproportionate amount of vaccine preventable diseases in racial, ethnic and underserved populations.

Although the reasons for these disturbing gaps are not well understood, it appears that disproportionate poverty, discrimination in the delivery of health services and the failure of health care organizations and programs to provide culturally competent health care to diverse racial, ethnic and cultural populations are all contributing factors.

- ***To improve the quality of services and health outcomes.***

Despite similarities, fundamental differences among people arise from nationality, ethnicity and culture, as well as from family background and individual experience. These differences affect the health beliefs and behaviors of both patients and providers. They also influence the expectations that patients and providers

have of each other. The delivery of high-quality primary health care that is accessible, effective and cost-efficient requires health care practitioners to have a deeper understanding of the socio-cultural background of patients, their families and the environments in which they live. Culturally competent primary health services facilitate clinical encounters with more favorable outcomes, enhance the potential for a more rewarding interpersonal experience and increase the satisfaction the individual receiving health care services.

Critical factors in the provision of culturally competent health care services include understanding of the:

- beliefs, values, traditions and practices of a culture;
- culturally-defined, health-related needs of individuals, families and communities;
- culturally-based belief systems of the etiology of illness and disease and those related to health and healing; and
- attitudes toward seeking help from health care providers.

In making a diagnosis, health care providers must understand the beliefs that shape a person's approach to health and illness. Knowledge of customs and healing traditions are indispensable to the design of treatment and interventions. Health care services must be received *and* accepted to be successful.

Increasingly, cultural knowledge and understanding are important to personnel responsible for quality assurance programs. In addition, those who design evaluation methodologies for continual program improvement must address hard questions about the relevance of health care interventions. Cultural competence will have to be inextricably linked to the definition of specific health outcomes and to an ongoing system of accountability that is committed to reducing the current health disparities among racial, ethnic and cultural populations.

- ***To meet legislative, regulatory and accreditation mandates.***

As both an enforcer of civil rights law and a major purchaser of health care services, the Federal government has a pivotal role in ensuring culturally competent health care services. Title VI of the Civil Rights Act of 1964 mandates that no person in the United States shall, on ground of race, color, or national origin, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance."

Organizations and programs have multiple, competing responsibilities to comply with Federal, state and local regulations for the delivery of health services. The Bureau of Primary Health Care, in its *Policy Information Notice* 98-23 (8/17/98), acknowledges that: *Health centers serve culturally and linguistically diverse communities and many serve multiple cultures within one center. Although race and ethnicity are often thought to be dominant elements of culture, health centers should embrace a broader definition to include language, gender, socio-economic status, housing status and regional differences. Organizational behavior, practices, attitudes and policies across all health center functions must respect and respond to the cultural diversity of communities and clients served. Health centers should develop systems that ensure participation of the diverse cultures in their community, including participation of persons with limited English-speaking ability, in programs offered by the health center. Health centers should also hire culturally and linguistically appropriate staff."*

The Maternal and Child Health Bureau, through its program efforts related to state accountability and Healthy People Year 2000/2010 Objectives includes an emphasis on cultural competency as an integral component of health service delivery. The National Health Promotion and Disease Prevention Objectives emphasize cultural competence as an integral component of the delivery of health and nutrition services.

State and Federal agencies increasingly rely on private accreditation entities to set standards and monitor compliance with these standards. Both the Joint Commission on the Accreditation of Healthcare Organizations, which accredits hospitals and other health care institutions, and the National Committee for Quality Assurance, which accredits managed care organizations and behavioral health managed care organizations, support standards that require cultural and linguistic competence in health care.

- ***To gain a competitive edge in the market place.***

The provision of publicly financed health care services is rapidly being delegated to the private sector. Issues of concern in the current health care environment include the marketing of health services and the cost-effectiveness of health care delivery. The potential for improved services lies in state managed-care contracts that can increase retention and access to care, expand recruitment and increase the satisfaction of individuals

seeking health care services. To reach these outcomes, managed care plans must incorporate culturally competent policies, structures and practices to provide services for people from diverse ethnic, racial, cultural and linguistic backgrounds.

- ***To decrease the likelihood of liability/malpractice claims.***
  Lack of awareness about cultural differences may result in liability under tort principles in several ways. For example, providers may discover that they are liable for damages as a result of treatment in the absence of informed consent. Also, health care organizations and programs face potential claims that their failure to understand health beliefs, practices and behavior on the part of providers or patients breaches professional standards of care. In some states, failure to follow instructions because they conflict with values and beliefs may raise a presumption of negligence on the part of the provider.

  The ability to communicate well with patients has been shown to be effective in reducing the likelihood of malpractice claims. A 1994 study appearing in the Journal of the American Medical Association indicates that the patients of physicians who are frequently sued had the most complaints about communication. Physicians who had never been sued were likely to be described as concerned, accessible and willing to communicate. When physicians treat patients with respect, listen to them, give them information and keep communication lines open, therapeutic relationships are enhanced and medical personnel reduce their risk of being sued for malpractice.

  Effective communication between providers and patients may be even more challenging when there are cultural and linguistic barriers. Health care organizations and programs must address linguistic competence—insuring for accurate communication of information in languages other than English.

Rationale for Cultural Competence: Policy Making Implications for Primary Health Care Organizations and Programs

In the past three years, the National Center for Cultural Competence (NCCC) has documented that policy is the most underdeveloped area of the current cultural competence initiatives within Maternal and Child Health (Title V) programs serving children with special health care needs and their families. This observation extends to other human services including primary health care, mental health, social services and education. A recent review of the literature reveals that many of the current health care initiatives lack the policies, planning procedures and institutional structures that support culturally competent practices at the community level. The NCCC recognizes that systematic efforts must be implemented by policy makers or planners of services in order to effect systems change, enhance quality of services and improve health care access and outcomes for racially, ethnically and culturally diverse groups.

The conceptual framework of the cultural competence model that is used by the NCCC is based on the following beliefs:

- there is a defined set of values, principles, structures, attitudes and practices inherent in a culturally competent system of care;
- cultural competence at both the organizational and individual levels is an ongoing developmental process; and
- cultural competence must be systematically incorporated at every level of an organization, including the policy making, administrative, practice and consumer/family levels.

A wealth of literature and other resources has been published and widely disseminated to assist practitioners and direct service providers to deliver culturally competent services. The integration of culturally competent principles within the policy realm of primary health care delivery systems remains a great challenge for many states, communities and programs.

The following checklist is targeted to individuals who have a role in the shaping of policy at the Federal, state, local and program levels. Policy makers may be board members of private agencies, public agency officials, legislators, commissioners, advisory committee members, agency directors and staff of consumer/family organizations. The goal of this checklist is to facilitate policy making that supports culturally and linguistically competent primary health care services. The questions directly relate to the six areas of rationale presented in this policy brief.

Checklist to Facilitate the Development of Culturally and Linguistically Competent Primary Health Care Policies and Structures

Does the primary health care system, organization or program have:

☐ A mission statement that articulates its principles, rationale and values for culturally and linguistically competent health care service delivery?

☐ Policies and procedures that support a practice model which incorporates culture in the delivery of services to racially, ethnically, culturally and linguistically diverse groups?

☐ Structures to assure for consumer and community participation in the planning, delivery and evaluation of its services?

☐ Processes to review policy and procedures systematically to assess their relevance for the delivery of culturally competent services?

☐ Policies and procedures for staff recruitment, hiring and retention that will achieve the goal of a diverse and culturally competent workforce?

☐ Policies and resources to support ongoing professional development and inservice training (at all levels) for culturally competent health care values, principles and practices?

☐ Policies to assure that new staff are provided with training, technical assistance and other supports necessary to work within culturally and linguistically diverse communities?

☐ Position descriptions and personnel/performance measures that include skill sets related to cultural competence?

☐ Fiscal support and incentives for the improvement of cultural competence at the board, agency, program and staff levels?

☐ Policies for and procedures to review periodically the current and emergent demographic trends for the geographic area it serves?

☐ Methods to identify and acquire knowledge about health beliefs and practices of emergent or new populations in service delivery areas?

☐ Policies and allocated resources for the provision of translation and interpretation services?

☐ Policies and resources that support community outreach initiatives for limited English proficient and/or non-literate populations?

☐ Requirements for contracting procedures, announcement of funding resources and/or development of request for proposals that include culturally and linguistically competent practices?

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VOICE: 800-788-2066 OR 202-687-5387 • FAX: 202-687-8899 • E-MAIL: CULTURAL@GUNET.GEORGETOWN.EDU

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For More Information...

For more information on the topics covered in this policy brief, please see the listing of resources below.

TOPIC AREA Eliminating Disparities in the Health Status of People of Diverse Racial/Ethnic Backgrounds

American Academy of Ambulatory Care Nursing. "Communicating Across Cultures: Valuing Diversity and Utilizing Cultural Competency in Health Care." *AAACN Viewpoint*, vol.18(5), 1996.

Centers for Disease Control and Prevention, Agency for Toxic Substances and Disease Registry. Office of the Associate Director for Minority Health. (policy statement). Atlanta, GA, 1998.

Community and Family Health Multicultural Work Group, Washington State Department of Health. Building Cultural Competence: A Blueprint for Action. Olympia, WA, 1995. (Originally published by The National Maternal and Child Health Resource Center on Cultural Competency for Children With Special Health Care Needs and Their Families, Austin, 1995).

TOPIC AREA Improving Quality of Services and Health Outcomes

Harvard Pilgrim Health Care. *The Diversity Journal*. (Brookline, MA, Harvard Pilgrim Health Care Incorporated, 1997).

Roizner, Monica. *A Practical Guide for the Assessment of Cultural Competence in Children's Mental Health Organizations*. Boston, MA, Judge Baker Children's Center., 1996.

Texas Department of Health, Center on Cultural Competency. Journey Towards Cultural Competency: Lessons Learned. Washington, DC, Health Resources and Services Administration, Maternal and Child Health Bureau, 1996.

The Robert Wood Johnson Foundation and the Henry J. Kaiser Family Foundation. Opening Doors: Reducing Sociocultural Barriers to Health Care. Washington, DC, 1997.

TOPIC AREA Responding to Current and Projected Demographics

Centers for Disease Control and Prevention, Agency for Toxic Substances and Disease Registry. "Minority Health is the Health of the Nation." December 1998: http://www.cdc.gov/od/admh/window/htm.

U.S. Department of Immigration and Naturalization Services. Fiscal Year 1996 Statistical Yearbook. Washington, D.C., 1996.

TOPIC AREA Gaining a Competitive Edge in the Marketplace

The Robert Wood Johnson Foundation and the Henry J. Kaiser Family Foundation. Opening Doors: Reducing Sociocultural Barriers to Health Care. Washington, D.C., 1997.

Ordering information for specific materials referenced in the resource list.

Building Cultural Competence: A Blueprint for Action
Washington State Department of Health
Maternal and Child Health Community
and Family Health
New Market Industrial Campus, Building #7
P.O. Box 47880
Olympia, WA 98504-7880
Phone: (360) 236-3504 or (206) 389-3052
Fax: (360) 586-7868

The Diversity Journal
Harvard Pilgrim Health Care
Office of Diversity
10 Brookline Place West
Brookline, MA 02146-7229
Phone: (617) 730-7710
Fax: (617) 730-4695

A Practical Guide for the Assessment of Cultural Competence in Children's Mental Health Organizations
The Technical Assistance Center for the Evaluation of
Children's Mental Health Systems
Judge Baker Children's Center
295 Longwood Avenue
Boston, MA 02115
Phone: (617) 232-8390
Fax: (617) 232-4125

Journey Towards Cultural Competency: Lessons Learned
The Maternal and Child Health Clearinghouse
Phone: (703) 821-8955
Fax: (703) 821-2098
Catalog Information: www.nmchc.org

Opening Doors: Reducing Sociocultural
Barriers to Health Care: Lessons Learned
National Program Office
c/o Hospital for Sick Children Health System
1025 Connecticut Avenue, NW, Suite 1100
Washington, DC 20036
Phone: (202) 974-4694
Fax: (202) 974-4695

About the

National Center for Cultural Competence

The National Center for Cultural Competence (NCCC) is a funded project of the Health Resources Services Administration (HRSA). The project is a collaboration between: the Maternal and Child Health Bureau's (MCHB) Division of Services for Children With Special Health Needs and its Infant and Child Health Branch; and the Bureau of Primary Health Care (BPHC). The mission of the NCCC is to increase the capacity of health care programs to design, implement and evaluate culturally competent service delivery systems. The NCCC is focusing on HRSA funded programs including: 1) Maternal and Child Health Title V programs concerned with children with special health needs and their families; 2) primary health care programs such as Community Health Centers, Migrant Health Centers, Health Care for the Homeless Grantees, Healthy Schools, Healthy Communities grantees, Primary Care Associations and Primary Care Offices; and 3) programs supporting families affected by Sudden Infant Death Syndrome and Other Infant Death.

The NCCC is a component of the Georgetown University Child Development Center, Center for Child Health and Mental Health Policy, and housed within the Department of Pediatrics of the Georgetown University Medical Center. For additional information contact:

The National Center for Cultural Competence
Georgetown University Child Development Center
3307 M Street, NW, Suite 401, Washington, DC 20007-3935
Voice: 800-788-2066 or 202-687-5387 • Fax: 202-687-8899
E-mail: cultural@gunet.georgetown.edu

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INSTITUTIONAL RACISM AND THE MEDICAL/HEALTH COMPLEX: A CONCEPTUAL ANALYSIS

Gary King, PhD

Presented in this paper is a theoretical framework for understanding and applying the concept of institutional racism to the medical/health care system. Medicine and health are viewed as vital social institutions that reflect the norms, values and social stratification systems of the larger society. Institutional or systemic patterns of racism are legitimated and promulgated through accepted standards, criteria, and organizational processes within the medical health complex that have the effect of discriminating against the minority group. It is maintained that racism is manifested (overtly or covertly) through history, ideology, community relations, research, education and the professions, and differential treatment. Focusing on investigators who have conducted studies of "racial bias" in the diagnosis and treatment of coronary artery disease, the author discusses some of the shortcomings of this research, from an institution racism perspective. Differential treatment researchers are encouraged to include social theory as part of their analysis and to explain the practical significance of their findings for the equitable delivery of health care. It is suggested that, because of wider structural changes occurring in American society, issues related to racism within medical and health institutions will become increasingly more important. (*Ethnicity Dis.* 1996;6:30–46)

Key Words: Institutional Racism, Minority Health, Medical Institutions, Coronary Artery Disease

> *. . . if it is shown that the level of health of some racially distinct group is markedly inferior, this situation would have to be called in part a racist consequence of the actions and structures of those health institutions. (Knowles and Prewitt, 1969)*

Introduction

Race and racism are enduring themes in the study of American society.[1-3] Social stratification on the basis of race and ethnicity is a powerful means by which societal resources are distributed and life chances are determined. Other principal structural determinants of social status include social class and gender. It is through this complex of power, privilege, and values that the interaction between members of majority and minority groups occurs.

The medical/health complex, consisting generally of organizations, professionals, and systems of delivery and production, reflects a society's history, culture, and social system.[4-9] In addition, it provides explanations of biologic functions and differences, human behavior and potential, improves the health of the population, and helps to determine social policy. As a result, the institution of medicine/health (and particularly the medical profession) is accorded certain privileges, resources and rewards, and autonomy that distinguishes it from other social institutions.[4-9]

Ideologies, practices, and policies concerning race that pervade or govern the general society are embodied in health organizations and systems through customs, standards and regulations. The medical/health complex also promotes the dominant racial group's interests and perspectives about the etiology, prevention and treatment of disease, systems of care, resource allocation and the education and distribution of providers.[4-9] A strong symbiotic relation-

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From the Department of Community Medicine and Health Care, University of Connecticut Health Center, Farmington, Connecticut.

Reprint requests to the Gary King, PhD, University of Connecticut Health Center, Department of Community Medicine, Farmington, CT 06030.

ship has existed and continues between the medical/health complex and the larger society with respect to majority/minority group relations and racial inequality. Historically, the medical/health establishment was as recalcitrant as any other social institution to change, internally or externally, racial injustice and discrimination (e.g., admitting more minority students; ending segregation and discrimination by professional medical societies and hospitals).[10-15] Albeit today it subscribes to a more enlightened commitment, the actions fall far short of what is needed to achieve equity within this important social realm. In a 1990 report, the Council of Ethical and Judicial Affairs of the American Medical Association concluded that the "health care system, like all other elements of society, has not fully eradicated racial prejudice."[16]

In recent years, critical attention has been given to the meaning of race in health and medicine, racial differences in health status, and "racial bias" and inequity in medical care.[17-24] Most of the empirical research identifying "racial bias" and differences in utilization, diagnosis and treatment have centered on coronary artery disease (CAD).[25-37] Other areas that have been investigated include health care access, renal dialysis and kidney transplants, breast cancer, HIV therapy, and prenatal care.[38-49] Most notably, but not discussed in this article, is research on racism in psychiatry and mental health services.[50-54]

The aims of this paper are to: 1) present a sociological paradigm of institutional racism; 2) discuss the broader application of this framework to the medical/health complex; and 3) to review critically conceptual and empirical approaches to the problem of differential treatment as presented in CAD studies.

INSTITUTIONAL RACISM

In 1967, as a "manifesto" for social change, Carmichael and Hamilton coined the term *institutional racism* to represent the systematic and more covert forms of racism that are perpetuated by dominant groups, social systems, and institutions.[55] They defined it as:

> less overt, far more subtle, less identifiable in terms of specific individuals . . . [it] originates in the operation of established and respected forces in the society and thus receives far less public condemnation than [individual racism].

Since their seminal discussion, extensive formulation of the concept (also referred to as systemic racism) has been conducted by social scientists who have assigned various practical meanings and theoretical applications.[54,56-65] In a critical review of the term, Williams criticizes social scientists for their lack of a strong theoretical paradigm; presenting simplistic, rhetorical and all inclusive descriptions; failing to advance empirical research; and not providing sufficient direction for policy development.[56]

Notwithstanding this criticism, the concept of institutional racism provides a valuable analytical framework to explore the structural legitimation and perpetuation of racial group dominance and disparities within the institution of medicine/health as well as other social structures (e.g., law, education) and countries.

First, as a conceptual tool, the term helps to clarify and distinguish between the actions of individuals who discriminate or are promotive of racial inequality and racial stratification resulting from structural impediments and processes.[65] As Williams maintains, individual racist attitudes and behavior, in and of themselves, are insufficient causes of racial inequity and social injustice.[56] Haas makes the points that institutional racism may exist "even when persons who make decisions for these institutions harbor no racial prejudice" or "without the victim being aware of how it [racism] operates."[62] Institutional racism is less of an indictment of individuals working within institutions than it is of the systematic operation of an institution. Opportuni-

ties for employment and promotion, criteria for selection and merit, historical traditions, professional power, social ideologies and the interdependence of social institutions are far more significant determinants of structural inequality than intentional discrimination by individuals.

Secondly, an institutional racism paradigm addresses the issue of effect and practice rather than intent[54,56-59,62] and by doing so, emphasizes the group as opposed to the individual consequences of racial oppression. In a compelling analysis of the shortcomings of Title 19 of the 1964 Civil Rights Act, Watson argues that the most pertinent grounds for legal redress of racial discrimination in health is a focus on its effect.[66] Also, basing his assessment on the effects (i.e., health status differences between blacks and whites) of systematic processes (rather than the attitudes or actions of individuals), Louis Sullivan, the former secretary of Health and Human Services, stated in 1991, "that there is clear, demonstrable, undeniable evidence of discrimination and racism in our health care system."[67]

Notwithstanding, an analysis employing the concept of institutional racism must also take into account the power of professionals or staff within an institution. Traditional conceptions of organizational behavior hold that individuals are essentially forced to subscribe to the institutional or bureaucratic structure's rules and regulations regarding social behavior including race-related issues. However, despite the changes taking place in the health care system, physicians (and to a lesser extent other health care professionals) possess a considerable amount of influence, autonomy and decision-making authority. Therefore, the actions and consequences (rather than intent) of individual authority figures (e.g., medical practitioners) should not be minimized or dismissed.[68]

Thirdly, because medical and health institutions are not totally insular organizations and systems unaffected or uninfluenced by other structures, an institutional racism framework examines the impact of external factors. Baron commenting on the "interconnectedness" of institutions and racial inequality, notes that resources and credentials acquired from one institution (e.g., education) are used as the achievement criteria for entry to another (e.g., medical school).[69] Consequently, minority groups that suffer from inadequate preparation by educational institutions are severely limited in opportunity to achieve in other sectors (e.g., medical school enrollment) thereby demonstrating the interrelationship between social institutions and the cumulative effects of societal racism.

Fourth, an institutional racism framework incorporates history and ideology as major determinants of contemporary racial inequality. Both factors have helped to advance systemic racism by defining and legitimating the primacy of tradition and the set of interconnected belief systems and values. For example, racial oppression in American society effectively excluded blacks from full and equal participation in medicine/health on the basis of white supremacist ideology (e.g., genetic inferiority, providential will).[73-75] The criteria for inclusion benefitted the dominant group and became the standards of merit and excellence whereby others (i.e., minority groups) could be "legitimately" excluded or restricted. This exclusion was sustained and perpetuated by the institutional practice of de facto and de jure segregation in practically all social spheres. As relations between majority and minority groups changed, exclusion or limitation became less intentional (i.e., overt) and more systemic (i.e., covert). Consequently, covert forms of systemic racism (e.g., traditions and standards of legitimacy) that excluded and oppressed racial minorities could achieve virtually the same results as the more overt expressions.

Fifth, a focus on institutional racism leads to recommendations and strategies to

change fundamental social inequities and systemic processes. This approach contrasts with perspectives that view the individual as the locus of the problem and assumes that "racism is a historical hangover, a form of ignorance to be remedied through academic re-education."[70] Also, it recognizes that persons and organizations that benefit from institutional racism are unlikely to voluntarily change the status quo.

Sixth, the concept of institutional racism acknowledges the role of other dimensions of social stratification; in particular, social class and gender. As a matter of fact, it is not possible to determine empirically the effects of institutional racism without controlling for other factors or variables such as social class and gender. Each of these structures independently and jointly impacts social and health statuses and produces differences (e.g., health status of women, black males) within majority and minority groups. Consequently, institutional racism cannot be viewed as a singular explanatory construct or be employed exclusively to explain all forms of differential effects or disparities in medicine/health.

Seventh, institutional racism has a dynamic character. It changes as affected by social forces, political movements and institutional transformations. Further, it may differ depending on the type of institution (e.g., hospital, community health clinic) and the norms and forms of inequality in a given society. Also, institutional racism need not be a permanent condition or phenomenon; moreover, no one racial or ethnic group is affected exclusively. Jews and other ethnic whites were also discriminated against by medical schools during earlier periods of American history.[74]

Lastly, in contrast to traditional approaches, an institutional racism analysis posits that the social meaning and impact of race on health occur not only through cultural factors (e.g., lifestyles, values), socio-political power (e.g., control or influence of vital social institutions) and socioeconomic status (e.g., income, education) but also via an ideologic and discriminatory component (i.e., racism).[24] In this connection, an institutional racism paradigm provides a critical analysis of the relationship between racial equality and medical/health institutions.

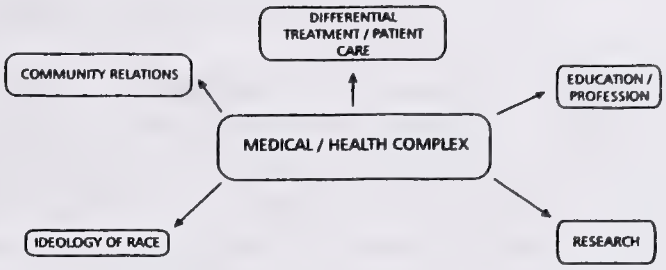

FIG 1.—Institutional Racism Model of the Medical/Health Complex.

INSTITUTIONAL RACISM IN MEDICAL AND HEALTH CARE

Although there have been few major studies of racism in medicine/health, there is little evidence suggesting that the problem is any less prevalent in this sector of society. Presented in Figure 1 is a diagram illustrating some of the significant dimensions or sectors of the medical/health complex in which an analysis of institutional racism would be valuable. They include: community relations, medical/health professions and education, medical/health research, differential treatment, and the ideology of race. As part of an interactive system, each sector can influence the process and outcome of events which occur in other spheres.

COMMUNITY RELATIONS

Relations, both current and historical, between medical/health organizations and minority communities can be viewed as indicators of an institution's resolve to prevent or redress discriminatory practices and to promote the social and health interests of minority communities. Community health promotion and disease prevention programs, public relations and outreach, location of health facilities, employment prac-

tices, participation on governing bodies, economic development and civic/political support are essential areas to examine in assessing the extent and character of relations between medical/health organizations and minority communities.[75]

MEDICAL/HEALTH PROFESSIONS

Noteworthy progress has been made in increasing minority health professionals since the late 1960s. For example, the decade of 1970–79 witnessed a 124% increase in the number of black students graduating from medical schools and the corresponding growth during the 1980 decennial period was 54%.[76] The number of physicians and health professionals who were women or from other minority groups also increased during these periods.[77] Despite these advances, enormous under-representation among African Americans, most Hispanic groups, and Native Americans remains in the medical/health professions.[77,78]

One reason for this under-representation is that admission to medical and other health professional schools is substantially determined by the social environment. Students' backgrounds, academic achievement, financial wherewithal, and the decisions of admission committee members, while obviously significant, are not the only relevant considerations.[78] From a sociological perspective, the process begins much sooner and involves a wider array of factors. The crisis of young black males is a prime example of the cumulative effects of the "interconnectedness" of social institutions and the transferability of institutional racism. The social degeneration of young African-American males through poor educational systems, substance abuse and organized criminal activity, media exploitation, inadequate social support systems and societal neglect is a major reason for the decreasing number of African-American males admitted to medical schools as well as other health professional institutions.[79]

The role of professional medical/health societies and organizations in promoting and sustaining institutionally sanctioned systems of control and dominance must also be studied. The historical record is replete with examples of racial exclusion especially by local medical societies and national organizations.[10-15] Despite provisions of the historic Hill-Burton Act prohibiting discrimination, civil litigation and activism were necessary to desegregate hospital facilities for black physicians and black patients.[10] The Richard DeFunis and Alan Bakke U.S. Supreme Court cases, which directly challenged the legitimacy of affirmation action programs in medical schools, are other examples of the interests of minority communities in conflict with those of the majority group.[80]

An extremely dishonorable example of blatant racism by a medical society was the recent publication of the "Jungle Fever" invitations to a reception sponsored by the Indiana State Medical Association to state legislators.[81] On official stationery, the invitation featured racist caricatures of cannibalism against whites and banana-eating, bone-in-the-nose depictions of Africans. This incident serves only as a reminder of past transgressions and present failings.

RESEARCH

The systemic exclusion of minority populations from biomedical and socio-behavioral research also represents a form of institutional racism. While investigators may not have attempted to deliberately exclude minorities and women from clinical trials and other research projects, oftentimes the selection of study topics, availability of funding, location, eligibility criteria, conceptual orientations and implementation strategies, and requirements for research subjects have reduced systematically the number of minority participants. Until fairly recently, federally funded research projects were not required to include minorities and women or explain why they should be excluded. Even when such a mandate ex-

ists, the efforts and results can be disappointing as in the case of the National Cancer Institute's (NCI) National Surgical Adjuvant Breast and Bowel Project. According to a 1993 report, of the more than 6,000 women enrolled in the NCI's tamoxifen trials, only 1.1% were black and 1.2% comprised the "other than white" category.[82]

The social and health costs incurred by past and present under-representation of these groups in research studies have not been fully evaluated.[83,84] Svensson in a review of 50 clinical trial studies published in the journal, *Clinical Pharmacology and Therapeutics,* found that "insufficient data exist to accurately assess the safety and efficacy of many new drugs in American blacks."[85] Dresser, commenting on "the white male bias" in biomedical projects, asserts that providers "lack adequate evidence on whether women and people of color will be helped, harmed or not affected at all by numerous therapies now endorsed as promoting 'human health'."[86]

Medical/health research conducted in minority communities must account for broader sociological factors. In poorer minority communities, researchers inevitably encounter the immense social problems of inadequate or non-existent infrastructures, lower income and educational levels, residents' fear of criminal activity, and different conceptions and priorities about health and medical care. These communities may also make demands of researchers such as representation on advisory boards and jobs (e.g., as recruiters, interviewers or outreach workers). In addition, the cultural dimension of different languages, norms, values and patterns of interaction, diet, and religious beliefs may also present formidable challenges.

Other major problems facing academic researchers and public health specialists are the history of exploitation, poor treatment, misinformation and the uncertainty about the use of research results. [75,87] Frequently, these professionals are viewed as representing the interests of medical/health institutions that have historically regarded minority communities with disdain and disinterest and have practiced overt and/or covert forms of racism. Hatch et al. discuss four different models of "a research partnership" with black communities.[75] The models range from one of minimal community input and participation to optimal collaboration in the direction and focus of the research.

Many researchers may have orientations, experiences, methodological approaches and protocols, and goals that are in conflict with, or are quite different from, the health priorities and aims of minority communities. Standardization and legitimation of research protocols only on the basis of the health problems, orientations, and the social experiences of the majority group can provide a fallacious rationale for systemic exclusion of minority groups.

Ideology

Medical and health institutions and professions embody a set of ideas, principles, values, beliefs and opinions that can be generally described as ideology.[4-9] This ideology has evolved from developments in the science, the background and political orientations of its members, the practice of medicine/health, and external social forces and changes. It influences the professional culture (e.g., norms, values and behaviors), relations of power vis a vis other institutions and groups (e.g., politics, education, economics), and professional orientations (e.g., medical model, recruitment and admission). Further, it serves to support and promote the professional and institutional interests of the medical/health establishment and its status and role in the larger society.

On matters of race and social issues, conflict frequently exists between the ideas, beliefs and opinions (i.e., ideology) of medicine/health institutions—especially with the medical profession—and minority groups.

The profession of medicine, for example, is part of the elite social echelon of the dominant group and generally has been supportive of the status quo and a conservative political and social agenda. This position contrasts sharply with the political interests and power of minority communities whose social progress has transpired as a result of directly confronting the status quo and demanding change.

By themselves, ideologic differences may not constitute institutional racism. However, an analysis employing an institutional racism paradigm helps to elucidate how seemingly "neutral" or innocuous belief systems and ideas are used to legitimate and defend a system of racial dominance. Hence, it is not possible to disassociate the political orientation of the institution or profession of medicine/health from its macro and micro relations with minority communities. Specifically, this involves "powersharing" in such areas as doctor/patient relations (e.g., demands for cultural competence, elimination of victim-blaming bias), resources (e.g., funding for prevention vs technology/invasive procedures), reform of the health care system (e.g., more equitable distribution of health services), medical education (e.g., more minority health professionals, training to increase social and cultural sensitivity), and electoral politics.

Moreover, this power imbalance, both in terms of social class and racial group status, is another important reason to study the ideologic nature of institutional racism and examine how differences in political ideas, interests and statuses between the medical profession and minority communities can lead to conflict and mistrust and make cooperation difficult.

Another fundamental aspect of ideology within the context of majority-minority group relations, is the ideas and scientific formulations about race that have developed in medicine/health. Part of the confusion about the concept of race stems from the postulation, promulgated by the medical model, of a discrete physiologic taxonomy of races.[17,19,23,63,88] The central thesis is that distinct genetic differences exist among so-called races that essentially determine intelligence, disease and illness, sexuality, cultural practices, and social mobility. Specifically, this viewpoint has served to confuse the social conception of race and equate the social etiology of behavior with erroneous and socially destructive conceptions of biological determinism. This ideologic argument was used to justify slavery,[71] inspire and advance the eugenics movement,[89] provide a rationale for separate and unequal social policies,[59,60] and serves presently to encourage and promote racism.

DIFFERENTIAL TREATMENT RESEARCH

Table 1 presents a typology illustrating the development of what Stoeckle and Zola referred to as "differential treatment" research.[90] For heuristic purposes, the typology has been divided into three periods: an "exploratory" research period that lacked methodological rigor; a "contemporary" period consisting mostly of CAD studies; and an "incisive" period in which researchers attempt to combine theory, methods, and policy considerations.

The research of early investigators such as Perkoff and Anderson, Egbert and Rothman and Shaw are included in the exploratory period.[91-93] Though not focusing on CAD, the distinguishing features of these few studies are that they: 1) represented developmental efforts in the use of quantitative methods to ascertain differences between blacks and whites in medical care and treatment; 2) were limited in the use of multivariate analyses to control or adjust for confounders; 3) generally predated the use of large national data bases to study "racial bias" and differential treatment in medicine/health; 4) occurred during a period of greater overt racism and social change in American society and consequently,

TABLE 1.—Some Studies Examining Differential Treatment Using Diagnostic and Treatment Procedures in Cardiovascular Care

Study	Finding	Variables Held Constant	Disease or Health Problem
Exploratory Period			
Egbert and Rothman *NEJM, July 14, 1977*	Blacks were 2.2 to 4.3 times more likely than whites to receive care from surgical residents.	Time (2 decades); Self-payment; Private insurance. Relationship disappeared after controlling for Medicaid.	Differential Treatment
Contemporary Period			
Oberman and Cutter *Am Heart J* 108: 688–694, 1984 Bl = 278 Wh = 6316	Only 4% of blacks underwent coronary arteriography compared to 96% of whites. When disease severity was controlled whites were almost twice as likely to have surgery than blacks.	Clinical manifestations; Predisposing factors; Time (1970–1978); Severity of disease. Survival was similar except for older blacks.	Arteriography or coronary artery bypass grafting Selection process for diagnostic evaluation and clinical decision for type of therapy
Maynard, Fisher, Passamani and Pullum *Am. J Pub Hlth* 76:1446–1448, 1986 Bl = 202 Wh = 13,105	Surgery was recommended to 46.5% of blacks and 59.4% of whites (Ratio, 1.13). Race was a significant predictor after controlling for occupation.	Similar clinical/angio-graphic characteristics; Occupational status.	Race and clinical decision making
CASS Registry Yergan, Flood, LoGerfo and Diehr *Med Care* 25:592–603, 1987 Nonwhites = 931 Whites = 3,433 17 hospitals	Nonwhite patients received fewer hospital services than expected after controlling for relevant factors.	Health status; Source of payment; Hospital site; Time (1970–1973).	Relationship between patient race and the intensity of hospital diagnostic and therapeutic services Pneumonia
Gillum *Am Heart J* 113:1255–60; 1987 Large sample size National Hospital Discharge Survey	The CABG and CA rates of whites was respectively 3.6 and 2.2 times higher than blacks.	In separate analysis; Region; Hospital; Size; Ownership, Type of payment; Marital status.	Coronary artery disease Differential treatment

TABLE 1.—Continued

Study	Finding	Variables Held Constant	Disease or Health Problem
Wenneker and Epstein *JAMA* 261:253–267; 1989 Blacks = 2,673 Whites = 106,902 MA Health Data Consortium	Whites underwent significantly more angiography (1.29) and CABG procedures (1.89).	Age; Gender; Source of payer; Income; Primary diagnoses; Number of secondary diagnoses.	Coronary artery disease Differential treatment
Exploratory Period Ford, et al. *Am J Public Health* 79: 437–440; 1989 Very large sample sizes National Hospital Discharge Survey	Black men had 77% the discharge rates of white men; 50% less CA and 33% less CABG surgery. Black women had a 19% lower rate of CA and 52% lower rate of CABG surgery. Blacks had higher rates of CA and CABG when controlling for public insurance but not for private insurance.	Time (1979–84); Acute myocardial infarction as index of relative need for health care; hospital ownership; Source of payment.	Coronary artery disease Coronary arteriography and Coronary bypass survey
Maynard, Litwin, Martin et al. *Am J Cardiol* 67:18–23, 1991 Blacks = 121 Whites = 2,749 MITI registry, Kings County WA	Blacks had lower rates of coronary angioplasty than whites (10% vs 18%) and coronary artery bypass graft surgery (4% vs 10%) than whites. Hospital mortality was lower for blacks but disappeared after adjusting for clinical an demographic variables.	Age; Gender; Clinical history; Admission symptoms; Symptom onset and time or arrival (constant only for HM).	Acute myocardial infarction Differential treatment
Gittelsohn, Halpern and Sanchez *Am J Public Health* 81: 1435–1441; 1991 Large sample size HSCRC, Maryland	Coronary and carotid artery surgery rates are 2–3 times higher among whites than blacks. The more discretionary the procedure the lower the incidence among blacks. Medical admission was higher among blacks.	Type of surgical procedure; Time (1985–1987); Gender; Income; Age.	Income, race and surgery
Hannan, Kilburn, O'Donnell et al. *Med Care* 29:430–441; 1991 Blacks = 5,962 Whites = 55,887 SPARCS, New York (1987)	Whites had 1.25 times more CA, 2.06 for CABG, and 1.69 for AN than did blacks. Whites after controlling for severity of disease and other key variables.	Age; Gender; Source of payment; Number of secondary diagnoses; Admission; and Estimated mean income of zip code.	Coronary artery disease Cardiac surgery

TABLE 1.—Continued

Study	Finding	Variables Held Constant	Disease or Health Problem
Goldberg, Hartz, Jacobsen et al. *JAMA* 267:1473–1477; 1992 Large sample size MEDPAR; BHP-ARF; Census (1986)	The CABG rate was 27.1 per 10,000 for whites; 7.6 for blacks; WM (40.4) vs BM (9.3); WW (16.2) vs BW (6.4).	Rates for AMI admissions; Geographic area; Need for care; and Supply of physicians.	Coronary artery disease Cardiac artery bypass graft surgery
Johnson, Lee, Cook et al. *An In Med* 118:593–601; 1993 Blacks = 1,374 Whites = 1,657 2 Hospitals Boston, Cincinnati Incisive Period	After adjustments were made for multiple clinical factors, a lower proportion (31% less) of blacks than whites were admitted to hospitals; 21% less likely to be triaged to coronary care unit; 76% less likely to under CABG. No difference in cardiac catheterization.	Time (1984–1986); Gender; Household income (zip code); Insurance status; Chest pain; Physical exam findings; Medical history; Electrocard; Evaluation; Events during hospital stay.	Coronary artery disease Differential treatment
Escarce, Epstein, Colby, Schwartz *Am J Public Health* 83:948–954 Large sample size HCFA 1986 Part B Data File	Whites were more than 3.0 times as likely as blacks to receive CABG, CA and twice as likely to receive coronary angiogram.	Independently adjusted for urban residence; Medicare/Medicaid status; Stress tests.	Coronary artery disease Differential treatment
Whittle, Conigliaro, Good, Lofgren *New Eng J Med* 329:621–627; 1993 Large Sample Size Veteran Hospital Patient Treatment File	White veterans were 1.38 times more likely to undergo cardiac catheterizing; 1.5 times, CA and 2.2 times, CABG than black veterans.	Discharge diagnosis, Coexisting conditions, Age, Marital status, Eligibility, Race, Region, Hospital. Time (1987–1991)	Coronary artery disease Differential treatment

many of the studies focused on "such things as admittance rates for Negroes, integrated hospital rooms, birth with a physician present";[92] 5) tended to be more condemning of institutions and the general society as opposed to individual practitioners for disparities in care; 6) only implicitly suggested "racial bias" and discrimination as possible causes; and 7) had a minimal impact on health policy and institutional change within medicine/health.

During the mid-1980s to the early 1990s (contemporary period), additional studies were conducted that mostly examined "racial bias" in the diagnosis and treatment of CAD. One of the principal works of this period was by Wenneker and Epstein.[29] These investigators were among the first to adjust for income, severity of disease, health insurance and demographic variables and to suggest "that racial inequalities exist in the provision of cardiac care." Building upon the work of Wenneker and Epstein, additional investigators also have found "racial bias" in the treatment of coronary heart disease after controlling for other variables (such as age, gender, severity of disease, comorbidity, health insurance status, income).[25-37]

Typically, these studies differed from the "exploratory period" in the following ways: 1) they entailed greater methodological rigor in the research design, collection of data, statistical adjustment for other variables, and more sophisticated analytic techniques; 2) statistically significant differences were found showing that whites had a greater likelihood of receiving CAD diagnostic services and treatment than blacks; 3) both hospital-based and national data sets for analysis were used; and 4) attempted to control for indicators of social class and health insurance status.

Despite these advances, most of the "contemporary period" studies have serious shortcomings when viewed from an institutional racism perspective. A uniform weakness is the lack of theory. None of the studies provide a sufficient social paradigm or theoretical framework (e.g., majority/minority group relations, historical context, ideology, social psychology) to define and explain "racial bias" and systemic discrimination in medicine/health. As a result, there is little discussion of the "interconnectedness" of social institutions and forces; the evolution of racism within the medical/health complex from historical conditions and ideology; and the effect of social structure (e.g., medical organizations and professions) on the actions of individuals. Medical/health institutions are depicted as independent entities unaffected by external factors or conditions including societal racism. These shortcomings minimize the sociological dynamics responsible for "racial bias" and suggest that the problem can be handled exclusively and optimally by the medical/health complex.

Interestingly, the term "racial bias" rather than racism is used in discussing differential treatment by virtually all of the authors. Conceptually, this characterization is a misnomer that is devoid of any substantive theoretical interpretation. It is also consistent with a medical model approach because it focuses on the individual rather than linking "bias" to a systemic pattern (e.g., medical education, professional practice norms, institutional demands) or the general society (e.g., history of oppression, present conditions). Moreover, employing terms such as "racial bias" can be viewed as an insidious attempt to escape the wrath of moral and political judgement. Solomos and Beck maintain that, "the writing on new racism shows how contemporary manifestations of race are coded in a language which aims to circumvent accusations of racism."[64]

As a partial explanation of treatment disparities, some investigators have suggested "cultural factors."[29,32,34] In this connection, culture is presumably equated with racial group status but is neither defined nor empirically substantiated as a relevant factor.

This interpretation, for example, could be valid due to strong religious beliefs or different conceptions of illness (e.g., pain, help-seeking behavior). However, what is missing from this assertion is the crucial point that cultural phenomena also are products of the social milieu and do not exist unaffected by the social environment, history or other forms of group experience. Thus, behavior attributed to "cultural factors" may actually reflect adaptation to the negative group experience (e.g., perceived racial hostility and/or discrimination, lack of control, distrust, dissatisfaction with care) of minorities with medical/health professionals and institutions; familial and social obligations; or a failure of institutions and professionals to address the belief systems lifestyle patterns of minority patients, families and communities. Insufficient attention and research about these issues can lead to simplistic assumptions, victim-blaming, and inaccurate assessments about the role of culture in patients' decisions to comply with the recommendations of medical/health professionals.

Somewhat surprisingly, few of the "contemporary period" studies offer specific policy recommendations to rectify differential treatment. The failure to provide policy direction stems in part from the absence of a socio-historical paradigm and the aversion or inadequacy of a medical model approach to examine substantively social problems. It is also related to a strong professional sensitivity to and protectiveness from evaluation and criticism of differences in patient care—especially by race. Regardless of the reasons, differential treatment researchers should discuss the policy implications of their findings in terms of the social costs, medical education, necessary preventive and remedial measures, health services research and the relationship between racism in medicine/health and the society at large.

Perhaps most representative of the "incisive period" or the recommended future direction of differential treatment research are the works of Escarce and his colleagues[35] and Whittle et al.[36]. Escarce et al. analyzed the utilization of 32 procedures and tests among a 5% national sample of Medicare enrollees and concluded that "there are pervasive racial differences in the use of medical services by elderly Americans that cannot be explained by differences in the prevalence of specific clinical conditions." The authors pose a fundamental question underlying an institutional racism framework: that is, whether their findings are isolated examples or represent a systematic pattern. In exploring this question, they discuss the "interconnectedness" of medical care to other social institutions and conditions. Specifically, they observed that because elderly blacks are more likely than their white counterparts to receive care from neighborhood health centers, hospital outpatient departments, or emergency rooms, they are also more likely to experience higher "organizational barriers" (e.g., long waiting times, less satisfactory patient-physician relationships and less continuity of care) to diagnosis and treatment. These public or non-private health settings are associated with low-income neighborhoods, which have fewer medical specialists and because of overcrowded and under-funded hospitals, have "limited access to costly medical services" and require long distance travel.

They also acknowledge that cultural preferences and health beliefs regarding recommendations for coronary bypass surgery are in part adaptive responses to a "longstanding experience with barriers to access and largely inferior health care." The recognition of this point places less emphasis on individuals and their "way of life" for disparities in health care.

Notwithstanding, the authors demonstrate the same timidity as most other researchers regarding the use of the term racism. They also failed to discuss or comment on the historical and ideological na-

ture of institutional racism; the problem of societal racism and its impact on the medical/health complex; intent versus effect character of systemic discrimination as well as its dynamic character; and the institutional and professional practices that may generate or encourage covert racism. Other than providing suggestions for additional research and monitoring of reform initiatives, they do not offer specific policy recommendations to address the problem.

In their review of the 1987-1991 hospital records of black and white veterans, Whittle et al., after controlling for a number of factors, found a consistent racial difference in invasive cardiac procedures.[36] In a more direct fashion than Escarce et al. they suggested "the existence of race-related inequities in our health care system." Moreover, these authors have advanced the use of the institutional racism concept in CAD research in three specific ways. First, they are among the first to use explicitly the term "racism" and refer to it as a systemic feature of the health care system. Secondly, they distinguish between subtle (covert) and overt racism. Thirdly, they maintain that differential treatment may result from subjective judgement in clinical care as well as through structural mechanisms such as "delivery systems that are unfriendly to members of certain cultures." They also acknowledge the importance of health education and the influence of patient preferences. However, the authors do not address other aspects of institutional racism including the historical significance, ideology, interconnectedness to other social institutions or its character (effect and change).

Also, while the use of multivariate statistical procedures is an indispensable asset for explicating the complexity of health services research, it should not be a mere technical exercise in quantitative analysis or the only approach to investigating racism within the medical/health complex. Limitations often exist in accessing data (especially hospital-based information), variables (e.g., zip code income derivations), professional and demographic information about providers and the types of analyses that can be conducted. The use of qualitative methods also can provide valuable insight through vignette studies, racial tester research, content analysis of professional/client relations, interviews with patients and significant others, and historical and contemporary examinations of medical/health systems, institutions and professions.

In sum, although the studies by Escarce and Whittle have advanced our understanding of the systematic patterns of racial discrimination in the application of medical care, additional conceptualization and research is needed.

SUMMARY

The significance of race and ethnicity to the medical/health complex is likely to increase due to inexorable and interdependent changes that are taking place in American society. For example, of the approximately six million immigrants who arrived between 1981 and 1990, most were either Hispanic or Asian.[94-96] Among African Americans, the growth rate results primarily from a natural increase, although there is a sizeable black immigrant population from the Caribbean. As a result, there will be many more encounters between these populations and the health care delivery system. Not only do these populations vary culturally but they also are predominantly younger, have less education and possess marginal economic skills. Generally, because the poor and minority groups disproportionately experience chronic illnesses and infectious disease problems, their utilization and interaction with the health care system are also likely to increase. Medical/health institutions and professionals will face greater challenges attempting to meet the multifaceted needs of a sociologically diverse population by providing different and more extensive preventive and community-oriented services.

Moreover, these groups have attained relative political power (e.g., elected and appointed persons to local, state and national offices, community organization and activism) and can influence the decision-making process, statutes (i.e., laws, regulations and standards) and the allocation of resources to the health care system.[97,98] This development, along with the likely reform of the health care system, will bring greater scrutiny and accountability and will likely force medical/health institutions, especially in urban areas, to monitor and address systemic discrimination so as to assure greater equity in services provided.

One of the implications of differential treatment research for present health care reform initiatives is that universal health insurance will be an insufficient mechanism for assuring equal access to medical/health facilities and services.[66,90,99] Structural impediments due to systemic forms of racism will influence not only the delivery of health care but also perceptions of the system of care and potential utilization. It is imperative that policymakers begin to address this neglected and overlooked area through research and monitoring, statutes, regulations and penalties, and a recognition of the multifaceted nature of institutional racism within medicine/health.

The studies reviewed in this article provide compelling evidence of differential treatment by race. Other forms of differential treatment that should be investigated include practitioner/client relations, internal institutional processes, and the perceptions and experiences of patients. As illustrated in Figure 1, differential treatment is but one manifestation of institutional racism in the medical/health complex.

Above and beyond, the problem of racism in medical/health institutions is part of a continuing social and moral crisis in American society. Considerable passivity exists about this problem and medical/health researchers are to be commended for studying and increasing our understanding of this invidious social issue. However, because present disparities in health status, health care, and opportunities of minorities within medicine/health have been attributed, in large measure, to structural inequities caused by racism, researchers who study differential treatment or any other aspect of institutional racism are obligated to explain the conceptual dimensions and discuss the practical significance and policy implications of their empirical research.

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Testimony of John A. Rich, M.D., M.PH.
Medical Director, Boston Public Health Commission
Joint Committee on Health Care—Oversight Hearing on Health Disparities
June 4, 2002

The Boston Public Health Commission—the City's health department-- has noted a number of racial and ethnic and other population-based disparities in health outcomes, and developed programs to begin to address these disparities.

We know that a large proportion of the African-Americans who live in the Commonwealth live in Boston, so the evidence from this city will give a sense of what is going on for this population. When we look at deaths from all kinds of cancer, Black Boston residents die at a higher rate than any other group. Black residents died from cancer at a rate of 300 per 100,000 Black residents—one-third higher than White residents, who died at a rate of 200 per 100,000. For prostate cancer, Black men died at a rate almost twice as high as White men.

Between 1994-1999, Black men died from HIV/AIDS –related causes at more than twice the rate of White men. Hispanic men died from AIDS at a rate over one and a half times as high as that of White men.

Black and Hispanic Boston residents die from strokes at almost one and a half times the rate of White residents. Among all groups, Black residents die at the highest rate from heart disease.

And I know you are familiar with the racial disparity that persists in infant mortality. The most recent figures show that Black babies die over four times as frequently as White babies.

Why do these disparities exist? The point I want to stress to the Joint Committee on Health Care, as you think about solutions, is that racial and ethnic disparities are related

to racism, not to biological differences. Race is essentially a social construct, not genetic or biological. Therefore race, when it appears as an important factor, is usually serving as a proxy for some other factor, including but not limited to poverty, racism, lack of equal opportunity, discrimination, exposure to environmental risks, lack of health insurance and other barriers to health care access. Improvement in health status for people of color can be addressed by focusing on these social and political issues but also on specific quality improvement initiatives of medical care providers and insurers.

Dr. Camara Phyllis Jones in an article in the American Journal of Public Health defines three kinds of racism: institutional, personally mediated and internalized. Institutional, structural racism maintains barriers to good health. Institutional racism is something we can be quite blind to; it is systemic, larger than individual providers and policymakers, it includes acts of omission as well as commission, and it is one of the most important factors affecting the health of communities of color. It is where the actions of the Commonwealth can make the greatest difference.

Many of the efforts currently underway in the city of Boston were the result of the leadership exhibited by President Clinton during his administration when he prioritized the elimination of racial disparities. In fact, the Healthy People 2010 blueprint for the nation's health developed under the direction of Dr. David Satcher, then Surgeon General and Assistant Secretary for Health, names the elimination of disparities as one of 2 core guiding principles. This forward thinking leadership was the impetus for the federal Centers for Disease Control REACH 2010 program established to eliminate racial and ethnic health disparities.

Three of the Boston programs use a critical model of building coalitions and working hand in hand with the community to come up with solutions. One of the most important ways to reduce racial and ethnic disparities is to ensure that the affected communities are at the table in health planning, policy-making and budget decisions. I recommend that the Committee support efforts such as these which build coalitions and community capacity to effect change in the systems affecting us.

Here in Boston we have two REACH 2010 programs, one to eliminate racial disparities in breast and cervical cancer among women of African descent and another which targets Boston elders. The mission of Boston's REACH 2010 Breast and Cervical Cancer Coalition is to create, through a partnership between public health, health care providers and the community, a culturally competent health care system which promotes screening, education, prevention, treatment, and access to care for Black women. But this effort goes further by addressing the need to increase the diversity of the health work force. Through REACH 2010, we are training women of color to be radiology technicians to ensure that African American women feel more comfortable in obtaining this critical diagnostic test.

REACH Boston Elders 2010 targets racial disparities among elders in the three areas of cardiovascular health, diabetes, and adult immunization. The Public Health Commission worked with the community to develop a coalition, survey attitudes among African-American elders and providers to create a health improvement plan for this population.

The Women's Health Demonstration Project (WHDP) works to eliminate racial disparities in birth outcomes in Boston by improving the health status of women of childbearing age. One aspect of insuring better care is case management to connect women to appropriate social services and the creation of a holistic health assessment to become a permanent part of the woman's medical record.

With regard to the conclusions of the IOM report, the greatest imperative is to address the effects of institutional racism. As I stated institutional racism is the bias that is deeply embedded in the structures of health care and are often invisible to the good-hearted providers who work in and administer these structures. I agree that we need better data to understand the problem. However substantial data already exists to support the conclusions of inequity. We do however need data systems to track progress and ensure accountability in eliminating racial differences in care both at the community level and at the level of health care systems.

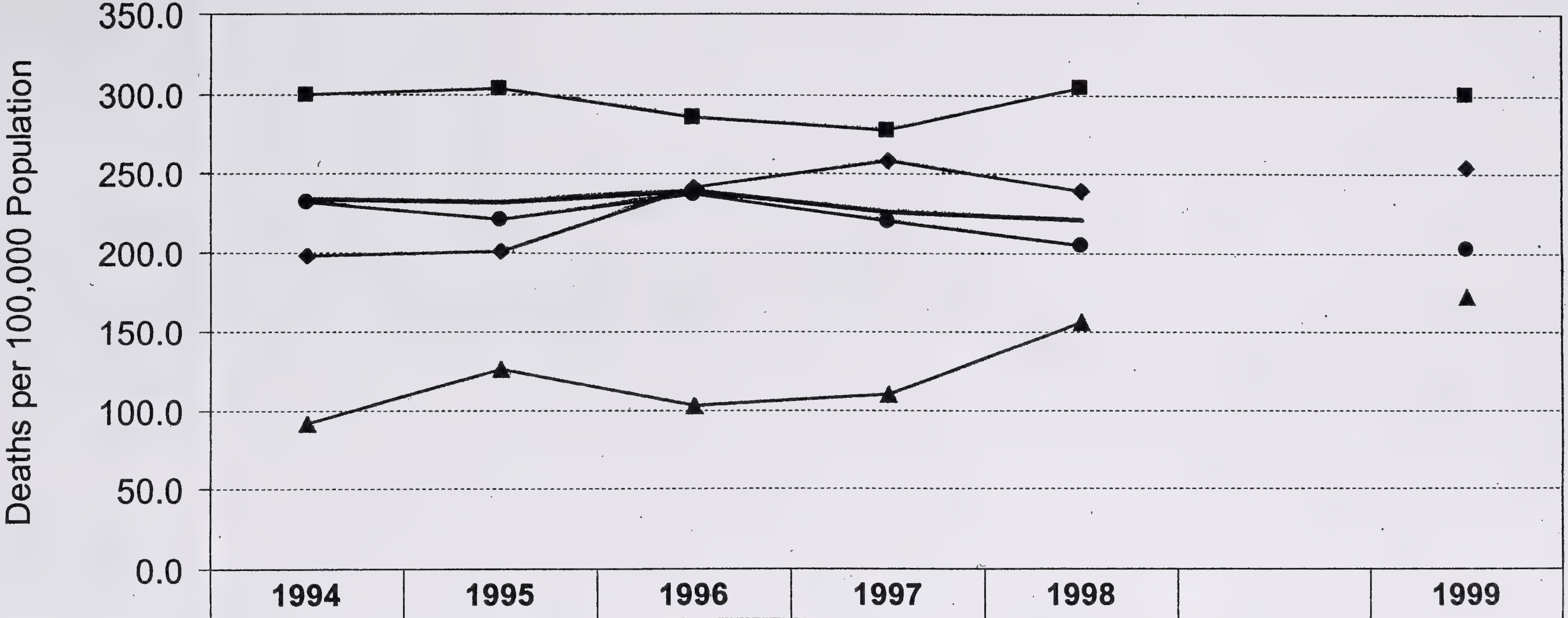
I believe we must focus our efforts on increasing the diversity of the health workforce not only at the physician level but also at the level of allied health professionals. We must find new and better ways to ensure that African Americans are represented at every level of health care delivery and public health. In addition, for those providers who are already in practice, we need to find new and better ways to train them to understand the social context from which their patients come, to recognize their own inherent biases and the biases of the systems in which they work.

We need to organize and educate affected communities so that they are empowered to both utilize the health care system and to be active participants in their care. While doing this, we must also work with individual institutions to ensure accountability through monitoring the quality of the care that they deliver to African Americans and other persons of color, and putting in place corrective strategies when inequities show themselves.

All of this will of course require that we continue to focus on removing barriers to health care utilization. One very important tool of access is health insurance. Even though racial disparities persist regardless of insurance status, we should make every effort to expand public insurance to those left out, and to make sure private insurance is available to those who work part-time, or in small businesses that do not offer health insurance benefits. For example, in order to eliminate racial disparity, the legislature would do well to preserve, and when possible, expand the MassHealth program, rather than weaken it.

I thank the Committee for its consideration of these issues and I look forward to working together to eradicate racial, ethnic and other health disparities.

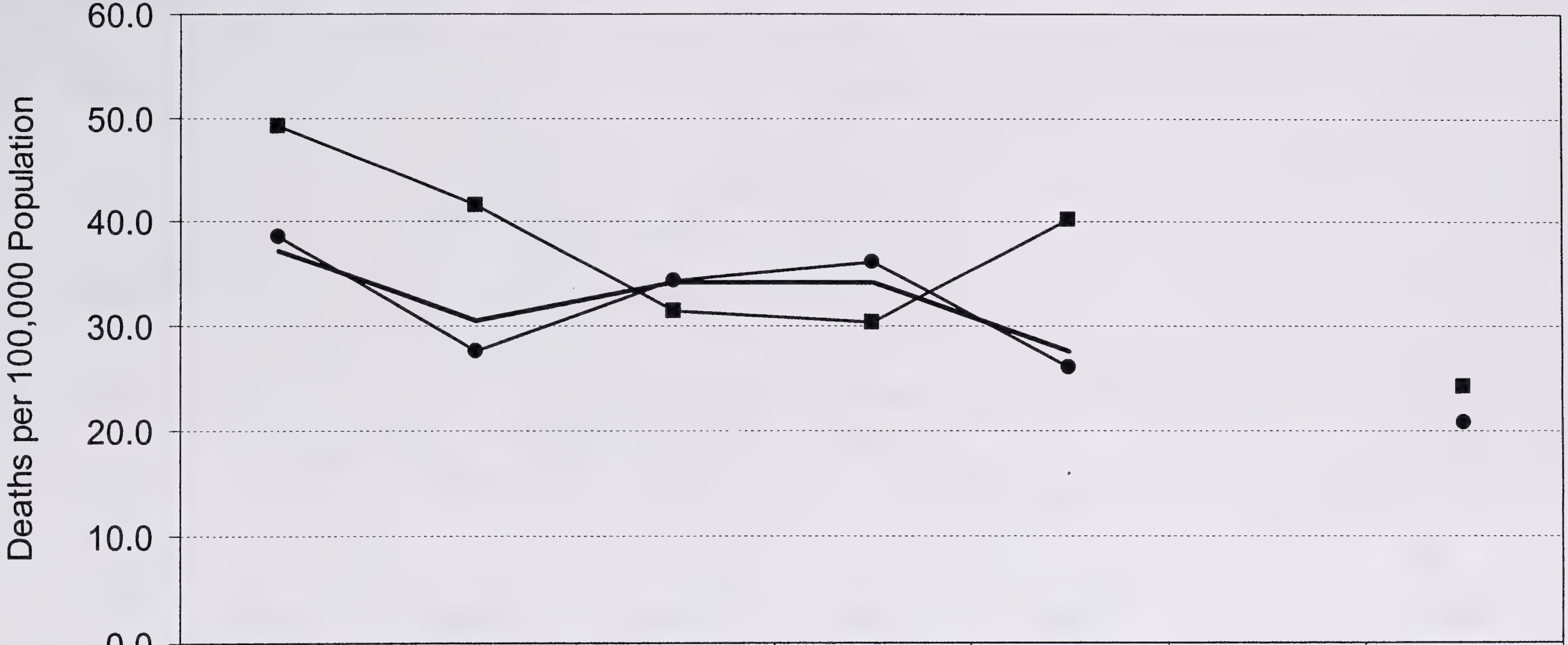
Cancer Mortality Age-Adjusted Rates by Race/Ethnicity
Boston, 1994-1999



	1994	1995	1996	1997	1998		1999
Boston	234.0	232.0	239.2	226.0	220.8		218.8
White	231.9	220.6	237.5	219.7	204.4		202.4
Black	299.1	303.9	285.0	277.8	304.5		300.8
Hispanic	91.9	126.5	103.0	110.2	156.0		172.3
Asian	198.1	200.8	241.2	258.5	239.1		253.7

NOTE: Age-adjusted to the 2000 US standard population.
DATA SOURCE: Boston resident deaths, Massachusetts Department of Public Health.
DATA ANALYSIS: Boston Public Health Commission, Research Office

Breast Cancer Mortality Age-Adjusted Rates by Race/Ethnicity
Boston, 1994-1999



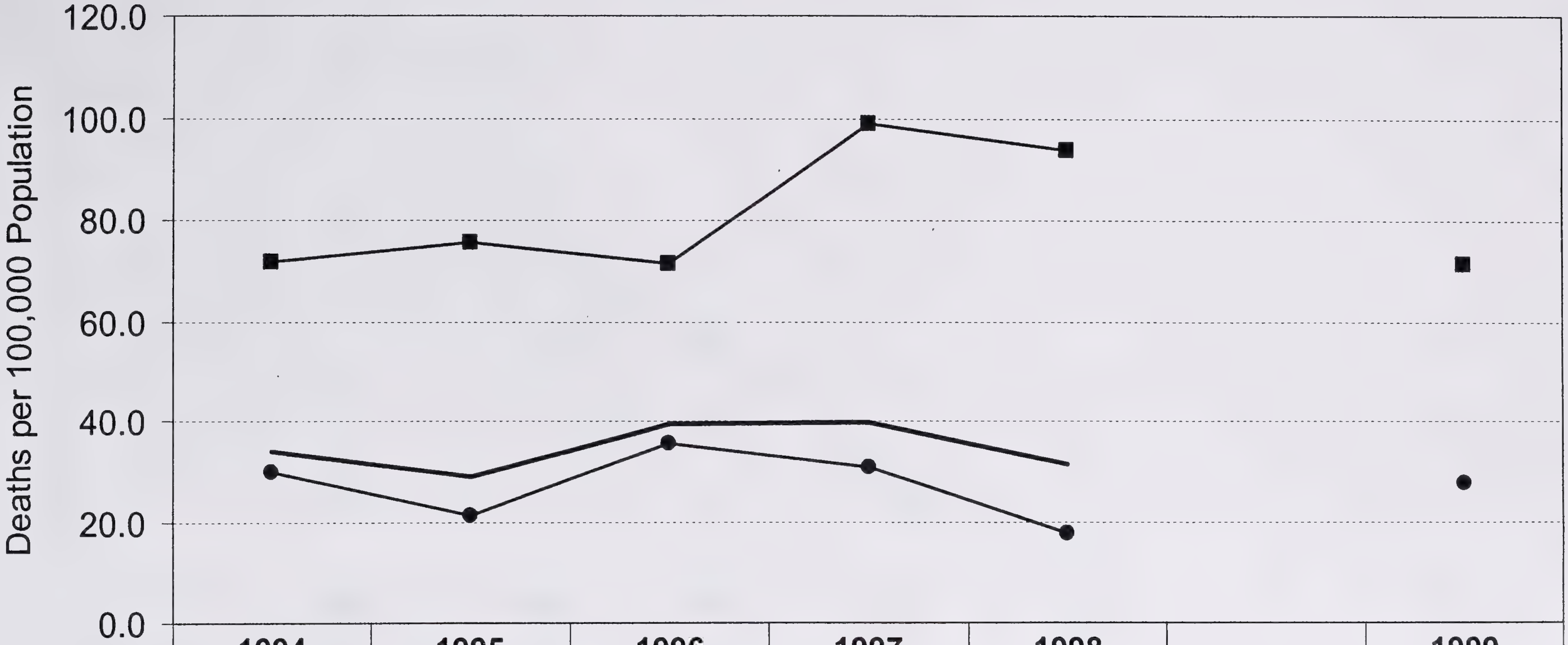
	1994	1995	1996	1997	1998		1999
— Boston	37.2	30.5	34.1	34.1	27.5		23.6
-●- White	38.6	27.6	34.3	36.1	26.0		20.7
-■- Black	49.2	41.6	31.4	30.2	40.2		24.2

NOTE: Rates are age-adjusted to the 2000 US standard population. For Hispanics and Asians, rates could not be presented because there were too few deaths in each of the years.

DATA SOURCE: Boston resident deaths, Massachusetts Department of Public Health.

DATA ANALYSIS: Boston Public Health Commission, Research Office

Prostate Cancer Mortality Age-Adjusted Rates by Race/Ethnicity
Boston, 1994-1999



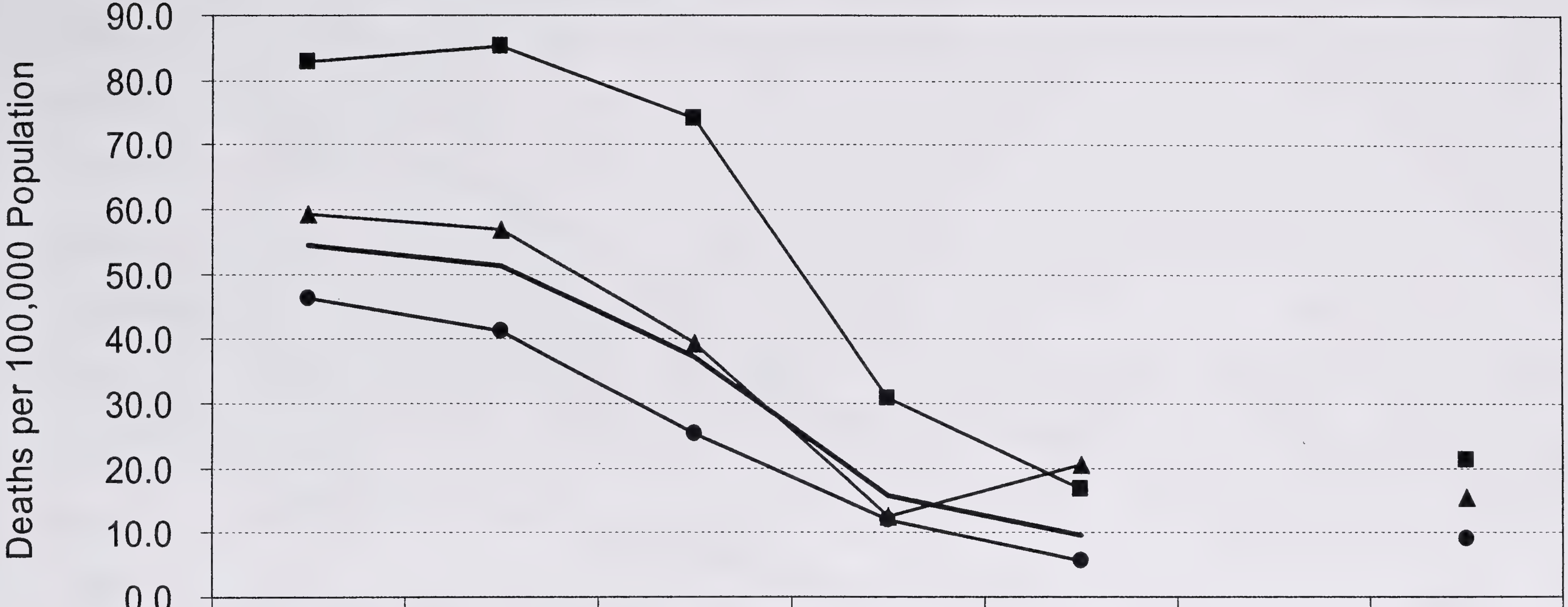
	1994	1995	1996	1997	1998		1999
— Boston	34.0	28.7	39.5	39.8	31.3		33.1
-●- White	29.6	21.1	35.4	30.7	17.6		27.5
-■- Black	71.6	75.5	71.3	98.9	93.9		71.4

NOTE: Rates are age-adjusted to the 2000 US standard population; For Hispanics, the rate for 1998 was 83.8; in each of the other years, rates could not be presented because there were too few deaths. For Asians, a rate could not be presented for any years, because there were too few deaths to calculate a rate.

DATA SOURCE: Boston resident deaths, Massachusetts Department of Public Health.

DATA ANALYSIS: Boston Public Health Commission, Research Office

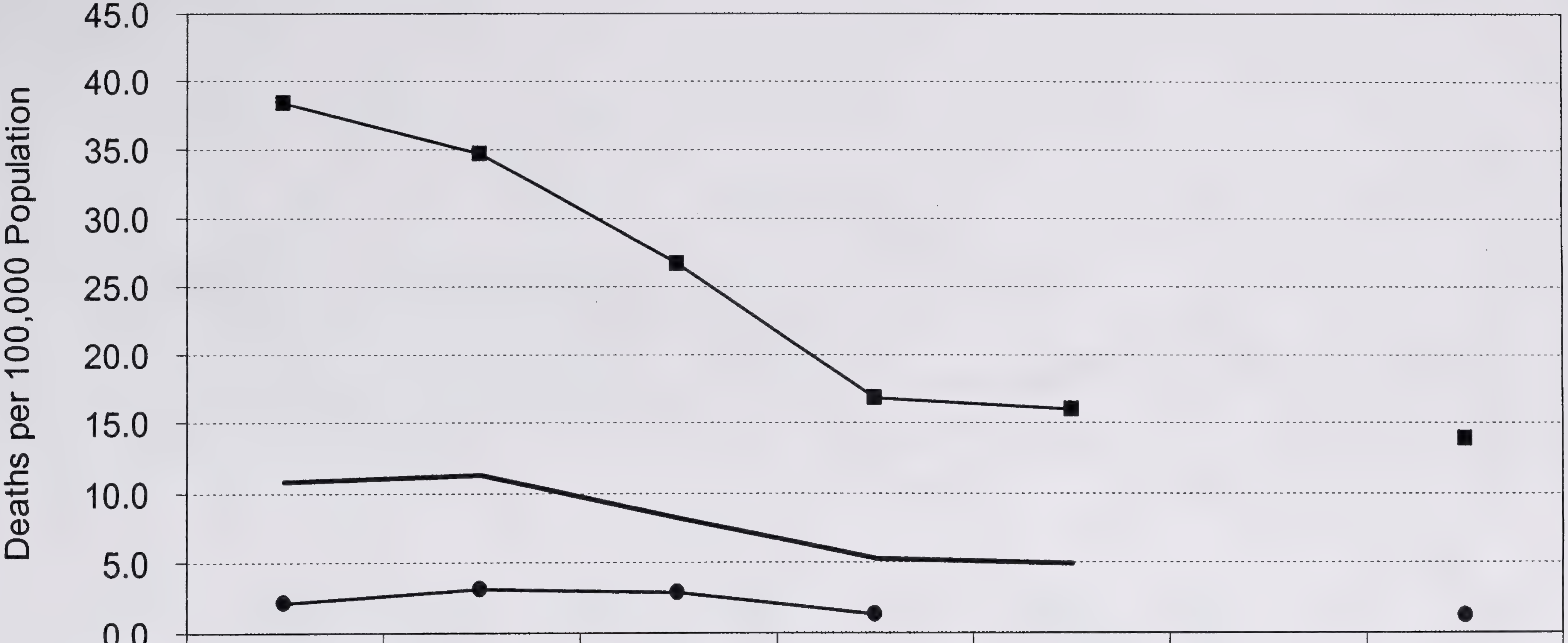
HIV/AIDS Mortality Age-Adjusted Rates by Race/Ethnicity
Boston, 1994-1999



	1994	1995	1996	1997	1998		1999
— Boston	54.3	51.2	37.2	15.7	9.5		12.3
● White	46.2	41.0	25.3	11.8	5.7		9.1
■ Black	82.8	85.3	74.2	30.7	16.6		21.2
▲ Hispanic	59.2	56.9	39.3	12.6	20.6		15.3
✳ Asian	n<5	n<5	n<5	n<5	n<5		n<5

NOTE: When there are fewer than five deaths (n<5), a rate cannot be presented; age-adjusted to the 2000 US standard population.
DATA SOURCE: Boston resident deaths, Massachusetts Department of Public Health.
DATA ANALYSIS: Boston Public Health Commission, Research and Technology Services.

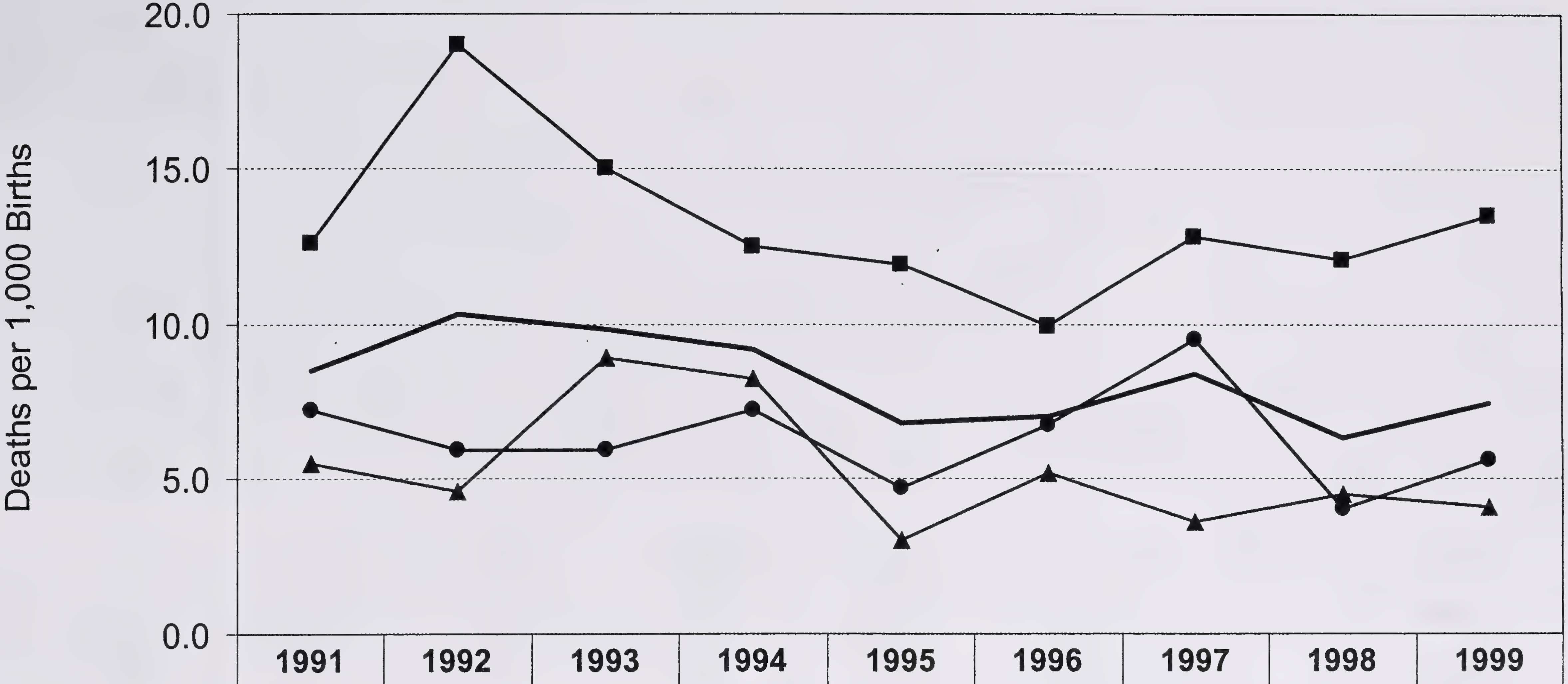
Homicide Mortality Age-Adjusted Rates by Race/Ethnicity
Boston, 1994-1999



	1994	1995	1996	1997	1998		1999
— Boston	10.8	11.2	8.2	5.2	4.9		4.3
-●- White	2.1	3.0	2.8	1.3	n<5		1.2
-■- Black	38.4	34.7	26.7	16.8	15.9		13.9

NOTE: When there are fewer than five deaths (n<5), a rate cannot be presented; For Asians, rates could not be presented for any yearage-adjusted to the 2000 US standard population.
DATA SOURCE: Boston resident deaths, Massachusetts Department of Public Health.
DATA ANALYSIS: Boston Public Health Commission, Research and Technology Services.

Infant Mortality Rates by Race/Ethnicity and Year
Boston, 1991-1999



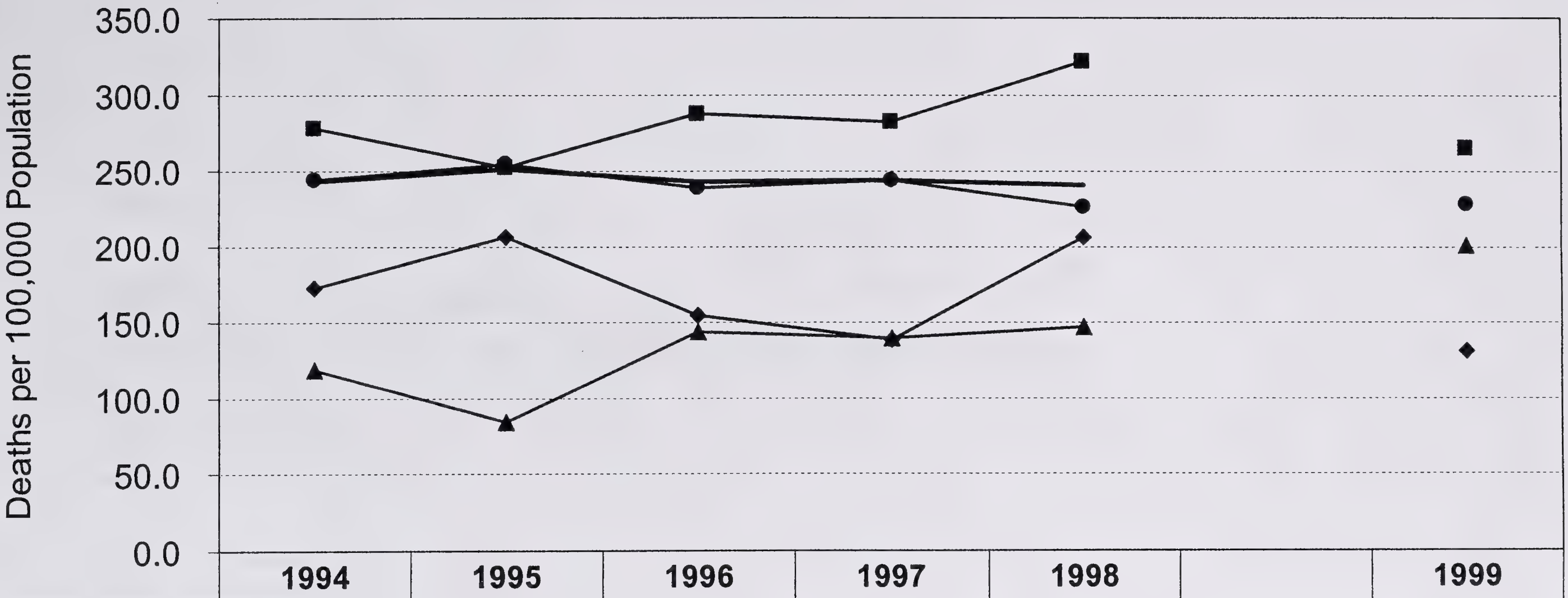
	1991	1992	1993	1994	1995	1996	1997	1998	1999
● White	7.2	5.9	5.9	7.2	4.7	6.7	9.5	4.0	5.6
■ Black	12.6	19.0	15.0	12.5	11.9	9.9	12.8	12.0	13.5
▲ Hispanic	5.5	4.6	8.9	8.2	3.0	5.2	3.6	4.5	4.1
— Boston	8.5	10.3	9.8	9.2	6.8	7.0	8.4	6.3	7.4

NOTE: Because some 1998 infant deaths were reported late, the 1998 IMR for Black infants, given in previous presentations, has been revised.

DATA SOURCE: Boston resident deaths and live births, Massachusetts Department of Public Health.

DATA ANALYSIS: Boston Public Health Commission, Research and Technology Services.

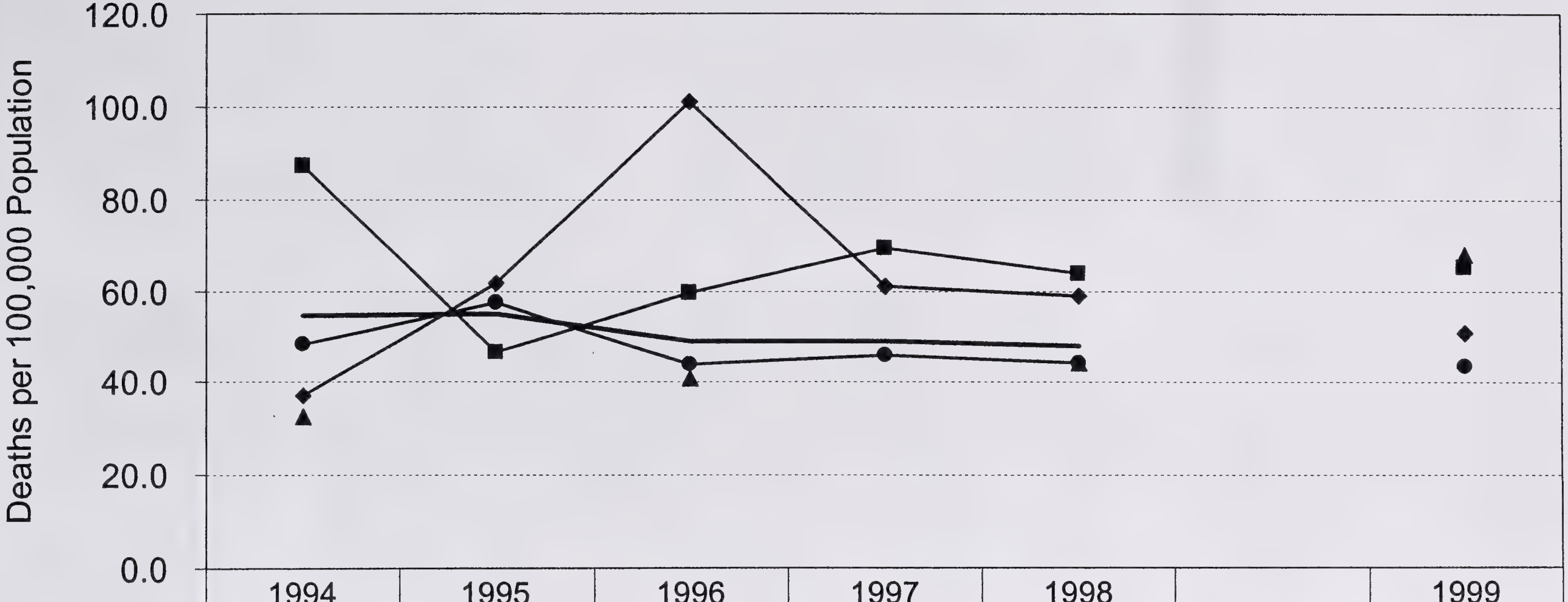
Heart Disease Mortality Age-Adjusted Rates by Race/Ethnicity
Boston, 1994-1999



	1994	1995	1996	1997	1998		1999
— Boston	243.0	251.2	243.0	243.7	240.5		231.8
—●— White	244.3	254.3	238.7	244.1	226.1		228.5
—■— Black	277.6	251.8	287.0	281.5	321.2		264.4
—▲— Hispanic	119.2	84.2	144.0	140.1	147.0		200.6
—◆— Asian	172.9	206.0	154.5	139.0	206.3		131.8

NOTE: Age-adjusted to the 2000 US standard population.
DATA SOURCE: Boston resident deaths, Massachusetts Department of Public Health.
DATA ANALYSIS: Boston Public Health Commission, Research and Technology Services.

Stroke Mortality Age-Adjusted Rates by Race/Ethnicity
Boston, 1994-1999



	1994	1995	1996	1997	1998		1999
— Boston	54.8	55.0	49.0	49.3	47.9		47.8
-●- White	48.4	57.4	44.0	46.1	44.3		43.5
-■- Black	87.1	46.8	59.4	69.1	63.6		65.1
-▲- Hispanic	32.6	n<5	40.8	n<5	44.2		67.8
-◆- Asian	37.1	61.5	101.0	60.9	58.9		51.0

NOTE: When there are fewer than five deaths (n<5), a rate cannot be presented; age-adjusted to the 2000 US standard population.
DATA SOURCE: Boston resident deaths, Massachusetts Department of Public Health.
DATA ANALYSIS: Boston Public Health Commission, Research and Technology Services.

Levels of Racism: A Theoretic Framework and a Gardener's Tale

Camara Phyllis Jones, MD, MPH, PhD

ABSTRACT

The author presents a theoretic framework for understanding racism on 3 levels: institutionalized, personally mediated, and internalized. This framework is useful for raising new hypotheses about the basis of race-associated differences in health outcomes, as well as for designing effective interventions to eliminate those differences.

She then presents an allegory about a gardener with 2 flower boxes, rich and poor soil, and red and pink flowers. This allegory illustrates the relationship between the 3 levels of racism and may guide our thinking about how to intervene to mitigate the impacts of racism on health. It may also serve as a tool for starting a national conversation on racism. (*Am J Public Health.* 2000;90:1212–1215)

Race-associated differences in health outcomes are routinely documented in this country, yet for the most part they remain poorly explained. Indeed, rather than vigorously exploring the basis of the differences, many scientists either adjust for race or restrict their studies to one racial group.[1] Ignoring the etiologic clues embedded in group differences impedes the advance of scientific knowledge, limits efforts at primary prevention, and perpetuates ideas of biologically determined differences between the races.

The variable race is only a rough proxy for socioeconomic status, culture, and genes, but it precisely captures the social classification of people in a race-conscious society such as the United States. The race noted on a health form is the same race noted by a sales clerk, a police officer, or a judge, and this racial classification has a profound impact on daily life experience in this country. That is, the variable "race" is not a biological construct that reflects innate differences,[2–4] but a social construct that precisely captures the impacts of racism.

For this reason, some investigators now hypothesize that race-associated differences in health outcomes are in fact due to the effects of racism.[5,6] In light of the Department of Health and Human Services' Initiative to Eliminate Racial and Ethnic Disparities in Health by the Year 2010,[7,8] it is important to be able to examine the potential effects of racism in causing race-associated differences in health outcomes.

Levels of Racism

I have developed a framework for understanding racism on 3 levels: institutionalized, personally mediated, and internalized. This framework is useful for raising new hypotheses about the basis of race-associated differences in health outcomes, as well as for designing effective interventions to eliminate those differences. In this framework, *institutionalized racism* is defined as differential access to the goods, services, and opportunities of society by race. Institutionalized racism is normative, sometimes legalized, and often manifests as inherited disadvantage. It is structural, having been codified in our institutions of custom, practice, and law, so there need not be an identifiable perpetrator. Indeed, institutionalized racism is often evident as inaction in the face of need.

Institutionalized racism manifests itself both in material conditions and in access to power. With regard to material conditions, examples include differential access to quality education, sound housing, gainful employment, appropriate medical facilities, and a clean environment. With regard to access to power, examples include differential access to information (including one's own history), resources (including wealth and organizational infrastructure), and voice (including voting rights, representation in government, and control of the media). It is important to note that the association between socioeconomic status and race in the United States has its origins in discrete historical events but persists because of contemporary structural factors that perpetuate those historical injustices. In other words, it is because of institutionalized racism that there is an association between socioeconomic status and race in this country.

Personally mediated racism is defined as prejudice and discrimination, where prejudice means differential assumptions about the abilities, motives, and intentions of others accord-

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The author is currently with the Department of Health and Social Behavior, Department of Epidemiology, and the Division of Public Health Practice, Harvard School of Public Health, Boston, Mass. She will soon begin working with the Centers for Disease Control and Prevention, Atlanta, Ga.

Requests for reprints should be sent to Camara Phyllis Jones, MD, MPH, PhD, Centers for Disease Control and Prevention, 4770 Buford Hwy, MS K45, Atlanta, GA 30341.

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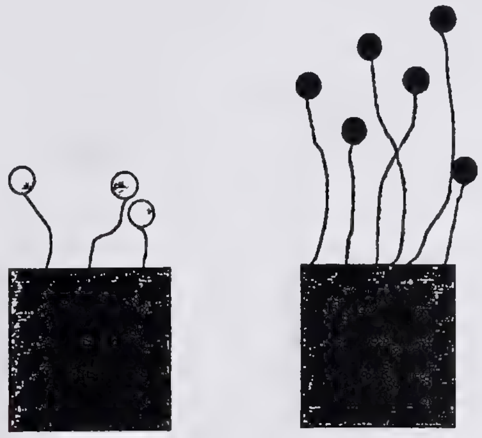
Institutionalized racism



- Initial historical insult
- Structural barriers
- Inaction in face of need
- Societal norms
- Biological determinism
- Unearned privilege

ing to their race, and discrimination means differential actions toward others according to their race. This is what most people think of when they hear the word "racism." Personally mediated racism can be intentional as well as unintentional, and it includes acts of commission as well as acts of omission. It manifests as lack of respect (poor or no service, failure to communicate options), suspicion (shopkeepers' vigilance; everyday avoidance, including street crossing, purse clutching, and standing when there are empty seats on public transportation), devaluation (surprise at competence, stifling of aspirations), scapegoating (the Rosewood incident,[9,10] the Charles Stuart case,[11–14] the Susan Smith case[15–18]), and dehumanization (police brutality, sterilization abuse, hate crimes).

Internalized racism is defined as acceptance by members of the stigmatized races of negative messages about their own abilities and intrinsic worth. It is characterized by their not believing in others who look like them, and not believing in themselves. It involves accepting limitations to one's own full humanity, including one's spectrum of dreams, one's right to self-determination, and one's range of allowable self-expression. It manifests as an embracing of "whiteness" (use of hair straighteners and bleaching creams, stratification by skin tone within communities of color, and "the white man's ice is colder" syndrome); self-devaluation (racial slurs as nicknames, rejection of ancestral culture, and fratricide); and resignation, helplessness, and hopelessness (dropping out of school, failing to vote, and engaging in risky health practices).

The following allegory is useful for illustrating the relationship between the 3 levels of racism (institutionalized, personally mediated, and internalized) and for guiding our thinking about how to intervene. I use this story in my teaching on "race" and racism at the Harvard School of Public Health as well as in my public lectures.

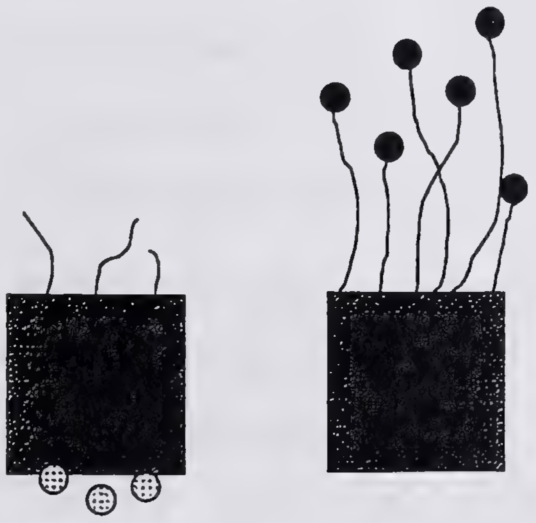
Levels of Racism: A Gardener's Tale

When my husband and I bought a house in Baltimore, there were 2 large flower boxes on the front porch. When spring came we decided to grow flowers in them. One of the boxes was empty, so we bought potting soil to fill it. We did nothing to the soil in the other box, assuming that it was fine. Then we planted seeds from a single seed packet in the 2 boxes. The seeds that were sown in the new potting soil quickly sprang up and flourished. All of the seeds sprouted, the most vital towering strong and tall, and even the weak seeds made it to a middling height. However, the seeds planted in the old soil did not fare so well. Far fewer seeds sprouted, with the strong among them only making it to a middling height, while the weak among them died. It turns out that the old soil was poor and rocky, in contrast to the new potting soil, which was rich and fertile. The difference in yield and appearance in the 2 flower boxes was a vivid, real-life illustration of the importance of environment. Those readers who are gardeners will probably have witnessed this phenomenon with their own eyes.

Now I will use this image of the 2 flower boxes to illustrate the 3 levels of racism. Let's imagine a gardener who has 2 flower boxes, one that she knows to be filled with rich, fertile soil and another that she knows to be filled with poor, rocky soil. This gardener has 2 packets of seeds for the same type of flower. However, the plants grown from one packet of seeds will bear pink blossoms, while the plants grown from the other packet of seeds will bear red blossoms. The gardener prefers red over pink, so she plants the red seed in the rich fertile soil and the pink seed in the poor rocky soil. And sure enough, what I witnessed in my own garden comes to pass in this garden too. All of the red flowers grow up and flourish, with the fittest growing tall and strong and even the weakest making it to a middling height. But in the box with the poor rocky soil, things look different. The weak among the pink seeds don't even make it, and the strongest among them grow only to a middling height.

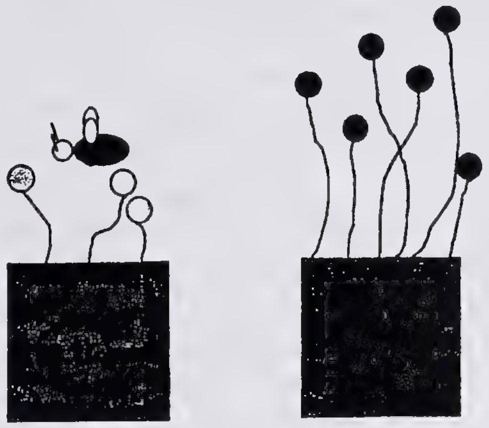
In time the flowers in these 2 boxes go to seed, dropping their progeny into the same soil in which they were growing. The next year the same thing happens, with the red flowers in the rich soil growing full and vigorous and strong, while the pink flowers in the poor soil struggle to survive. And these flowers go to seed. Year after year, the same thing happens. Ten years later the gardener comes to survey her garden. Gazing at the 2 boxes, she says, "I was right to prefer red over pink! Look how vibrant and beautiful the red flowers look, and see how pitiful and scrawny the pink ones are."

Personally mediated racism



- Intentional
- Unintentional
- Acts of commission
- Acts of omission
- Maintains structural barriers
- Condoned by societal norms

Internalized racism



- Reflects systems of privilege
- Reflects societal values
- Erodes individual sense of value
- Undermines collective action

This part of the story illustrates some important aspects of institutionalized racism. There is the initial historical insult of separating the seed into the 2 different types of soil; the contemporary structural factors of the flower boxes, which keep the soils separate; and the acts of omission in not addressing the differences between the soils over the years. The normative aspects of institutionalized racism are illustrated by the initial preference of the gardener for red over pink. Indeed, her assumption that red is intrinsically better than pink may contribute to a blindness about the difference between the soils.

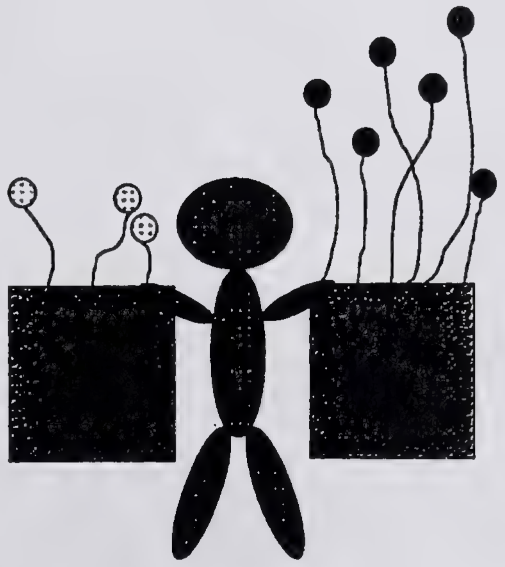
Where is personally mediated racism in this gardener's tale? That occurs when the gardener, disdaining the pink flowers because they look so poor and scraggly, plucks the pink blossoms off before they can even go to seed. Or when a seed from a pink flower has been blown into the rich soil, and she plucks it out before it can establish itself.

And where is the internalized racism in this tale? That occurs when a bee comes along to pollinate the pink flowers and the pink flowers say, "Stop! Don't bring me any of that pink pollen—I prefer the red!" The pink flowers have internalized the belief that red is better than pink, because they look across at the other flower box and see the red flowers strong and flourishing.

What are we to do if we want to put things right in this garden? Well, we could start by addressing the internalized racism and telling the pink flowers, "Pink is beautiful!" That might make them feel a bit better, but it will do little to change the conditions in which they live. Or we could address the personally mediated racism by conducting workshops with the gardener to convince her to stop plucking the pink flowers before they have had a chance to go to seed. Maybe she'll stop, or maybe she won't. Yet, even if she is convinced to stop plucking the pink flowers, we have still done nothing to address the poor, rocky condition of the soil in which they live.

What we really have to do to set things right in this garden is address the institutionalized racism. We have to break down the boxes and mix up the soil, or we can leave the 2 boxes separate but fertilize the poor soil until it is as rich as the fertile soil. When we do that, the pink flowers will grow at least as strong and vibrant as the red (and perhaps stronger, for they have been selected for survival). And when they do, the pink flowers will no longer think that red pollen is better than pink, because they will look over at the red flowers and see that they are equally strong and beautiful. And although the original gardener may have to go to her grave preferring red over pink, the gardener's children who grow up seeing that pink and red are equally beautiful will be unlikely to develop the same preferences.

Who is the gardener?



Government

- Power to decide
- Power to act
- Control of resources

Dangerous when

- Allied with one group
- Not concerned with equity

This story illustrates the relationship between the 3 levels of racism. It also highlights the fact that institutionalized racism is the most fundamental of the 3 levels and must be addressed for important change to occur. Finally, it provides the insight that once institutionalized racism is addressed, the other levels of racism may cure themselves over time. Perhaps the most important question raised by this story is *Who is the gardener?* After all, the gardener is the one with the power to decide, the power to act, and the control over the resources.

In the United States, the gardener is our government. As the story illustrates, there is particular danger when this gardener is not concerned with equity. The current Initiative to Eliminate Racial and Ethnic Disparities in Health by the Year 2010 is to be lauded as the first explicit commitment by the government to achieve equity in health outcomes.

Many other questions arise from this simple story. What is the role of public health researchers in vigorously exploring the basis of pink–red disparities, including the differences in the soil and the structural factors and acts of omission that maintain those differences? How can we get the gardener to own the whole garden and not be satisfied when only the red flowers thrive? If the gardener will not invest in the whole garden, how can the pink flowers recruit or grow their own gardener?

The reader is invited to share this story with family members, neighbors, colleagues, and communities. The questions we raise and the discussions we generate may be the start of a much-needed national conversation on racism. ☐

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WHEREAS: A health disparity gap exists for African American in comparison to the U.S. population as a whole[1]

WHEREAS: African Americans receive poorer medical care than whites in areas ranging from diabetes to mental health[2]

WHEREAS: The prevalence of diabetes in African Americans is approximately 70% higher than whites; racial and ethnic populations have higher rates of hypertension; and African Americans have a cancer death rate of approximately 35% higher than that for whites[3] and only 33% of African Americans released from inpatient mental care receive follow up care versus 54% of whites[4]

WHEREAS: The disparities recorded may have resulted in one additional death among every 200 patients treated[5]

WHEREAS: Racial/ethnic disparities in health results in lower health and wellness status for African Americans[6]

NOW THEREFORE BE IT RESOLVED that Delta Sigma Theta will lobby congress and state legislatures for increased funding to continue initiatives targeted to eliminate racial health disparities by 2010.

BE IT ALSO RESOLVED that Delta Sigma Theta will advocate for the allocation of funds for research by African American researchers, historically black colleges and universities (HBCUs) and other black organizations involved in health care delivery and research.

BE IT FINALLY RESOLVED that Delta Sigma Theta will encourage and support health and wellness programs for the African American community including efforts to promote the inclusion of African Americans in all phases of biomedical research.

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[1] U.S. Department of Health and Human Services, "Closing the Health Gap: Reducing Health Disparities Affecting African Americans", November 2001.
[2] Boston Globe, "Study Says Blacks Get Poorer Medical Care", March 13, 2002, p. A1.
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"Closing the Health Gap": Reducing Health Disparities Affecting African-Americans

Overview: "Closing the Health Gap" is a health information and education campaign designed to integrate health messages into the regular programming of ABC Radio Networks and ABC Radio's Urban Advantage Network. The partnership between HHS and ABC Radio aims to inform and educate African-Americans about the health gap and empower individuals to adopt healthier lifestyles. "Closing the Health Gap" supports HHS' efforts to eliminate racial and ethnic health disparities and the goals of Healthy People 2010, the nation's prevention agenda for improving public health.

Background: As part of HHS' Initiative to Eliminate Racial and Ethnic Disparities in Health, HHS is focusing on six major areas in which racial and ethnic minorities experience serious disparities in health access and outcomes - diabetes, heart disease and stroke, cancer, infant mortality, child and adult immunization and HIV/AIDS. Eliminating health disparities is also a major goal of Healthy People 2010, the nation's prevention agenda. Through "Closing the Health Gap," HHS and ABC Radio Networks will include health education segments that address the major focus areas of HHS' health disparities initiative, as well as other health issues relevant to African-Americans.

Health Disparities Affecting African Americans

Disparities in the burden of death and illness experienced by African-Americans, as compared with the U.S. population as a whole, have existed since the government began tracking such statistics. These disparities persist, and in some areas continue to grow. The following statistics illustrate some of the major areas of concern for African-Americans.

Life Expectancy and Death Rates

At birth, the average life expectancy for African-Americans is 71.8 years, compared to 77.4 years for whites. Life expectancy at birth for black males is 68.3 years, compared with 74.8 years for white males. Life expectancy at birth for black females was 75 years, compared with 80 years for white females. Almost 282,000 African-Americans died in

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2000. The age-adjusted death rate for the black population was 30 percent higher than for the non-Hispanic white population.

Diabetes

In 1999, 11,927 African-Americans died from diabetes, the sixth leading cause of death for this population. The African-American death rate due to diabetes was more than twice that for whites, when differences in age distribution were taken into account. In addition to the deaths it causes, diabetes may result in serious complications, including kidney disease, blindness, and amputations.

Heart Disease

In 1999, 78,574 African-Americans died from heart disease, the leading cause of death for all racial and ethnic groups. African-Americans were 30 percent more likely to die of heart disease than whites when differences in age distributions were taken into account.

Cancer

In 1999, 61,951 African-Americans died from cancer, the second leading cause of death for all racial and ethnic groups. In 1999, African-Americans were 30 percent more likely to die of cancer than whites when differences in age distributions were taken into account.

Infant Mortality

According to Health, United States 2000, infant mortality rates are more than twice as high for African-Americans (14.6 infant deaths per 1,000 live births in 1999) than for whites (5.8 infant deaths per 1,000 live births). There were 8,822 infant deaths in 1999.

HIV/AIDS

In 1999, 7,893 African-Americans died of HIV/AIDS, the sixth leading cause of death for African-American males, and the 10th leading cause of death for African-American females. In 2000, 47 percent of all cases reported in the U.S. were among African-Americans, and the rate of new AIDS cases among African-Americans was almost 10 times higher than among non- Hispanic whites. In AIDS cases among all African-American females, 55 percent were due to injection drug use or sex with an injecting drug user.

Stroke

In 1999, 18,884 African-Americans died from stroke, the third leading cause of death for all racial and ethnic groups. African-Americans were

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40 percent more likely to die of stroke than whites in 1999, when differences in age distributions were taken into account.

Homicide

In 1999, 7,648 African-Americans died from homicide, the eighth leading cause of death for this population. African-Americans were 5.4 times as likely as whites to die of homicide in 1999, even when differences in age distributions were taken into account. Homicide was the leading cause of death for black males ages 15-34.

Women's Health

African-American women are less likely to receive care, and when they do receive it, are more likely to have received it late. For example, one out of four African-American mothers did not receive prenatal care during the first trimester during 1999. Obesity is a risk factor for heart disease, diabetes, and stroke. Approximately 69 percent of African-American women between the ages of 20 and 74 were overweight during the period 1988 through 1994.

Immunizations

One out of four African-American children aged 19-35 months old did not receive recommended vaccinations in 1999. About 47 percent of elderly African-Americans received the flu vaccine in 1998, compared with 66 percent of elderly whites. About 26 percent of elderly African-Americans received a pneumonia vaccine in 1998, compared with 50 percent of elderly whites.

Substance Abuse

In 2000, approximately one-third of new AIDS cases among African-American women were due to injection drug use or sex with an injection drug user. Recent illicit drug use was more common among African-American adults (8 percent) than among white adults (5.7 percent) in 1998. However, African-American teenagers ages 12-17 years were less likely to use alcohol, marijuana or cocaine than white teenagers in 1999.

Mental Health

According to the 2001 Surgeon General's report on mental health, the prevalence of mental disorders is believed to be higher among African-Americans than among whites, and African Americans are more likely than whites to use the emergency room for mental health problems. African Americans with depression were less likely to receive treatment than whites (16 percent compared to 24 percent). Only 26 percent of African-Americans with diagnosed generalized anxiety disorder

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received treatment for their disorder, compared with 39 percent of whites with a similar diagnosis.

Organ and Tissue Donation

Currently, 21,140 African-Americans are on waiting lists for organ transplants, according to the United Network for Organ Sharing. African-Americans comprised 35 percent of the waiting lists for kidney transplants. African-Americans are almost four times as likely to have end-stage renal disease than whites, but they are less likely to be evaluated and placed on waiting lists for kidney transplants in a timely manner. Once on the list, they also tend to wait longer for a transplant. Exact causes are unclear.

Family Caregiving

African-American caregivers are more likely than other groups to report dementia and stroke in their care recipients - adding to the demands of their responsibilities. A higher proportion of black caregivers report having suffered physical and mental health problems a result of caregiving.

Suicide

In 1999, African-Americans were half as likely to die of suicide in 1999 than whites, even when differences in age distributions were taken into account. Still, 463 African-Americans ages 15-24 died from suicide in 1999. It was the third leading cause of death for blacks in this age group. Between 1980 and 1995, the suicide rate among African-Americans ages 10-14 increased 233 percent, while the rate for whites increased 120 percent.

Sources: HHS publications, unless otherwise noted.

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Study says blacks get poorer medical care

By Anne Barnard, Globe Staff, 3/13/2002

African-Americans receive poorer medical care than whites in areas ranging from diabetes to mental health, researchers at Harvard University say, in one of the broadest studies to date of racial disparities in health care.

For the first time, researchers looked at federal quality-control records for patients in Medicare managed-care plans. In examining 305,000 cases, they found that blacks were less likely to receive adequate care in all four areas measured: eye exams for diabetics, preventive drugs after a heart attack, breast cancer screening, and follow-up care after leaving a mental hospital. They said the differences were not fully explained by socioeconomic gaps.

The study, published in today's Journal of the American Medical Association, was the first large-scale research on race as a factor in mental health care, the category where it found the largest gap. Blacks released from inpatient mental care received follow-up care 33 percent of the time, compared with 54 percent for whites - itself a dismal percentage, said Dr. Eric Schneider of the Harvard School of Public Health, the study's lead author.

In recent years, enough studies have documented racial differences in health care that former surgeon general Dr. David Satcher declared "closing the health care gap" a national priority. But deciphering the reasons for the gap and finding solutions have proved difficult.

A study last week suggests that doctors and their minority patients may simply have trouble talking to each other.

"There is good reason to think that some of this disparity relates to problems in patient-physician communication," said Dr. Karen Scott Collins, lead author of a study released last week by the Commonwealth Fund, a nonprofit organization that researches health care issues.

Collins's report, which surveyed patients by telephone, found that minorities are more likely to report having trouble communicating with doctors, feeling disrespected in a doctor's visit, and not understanding or not following a doctor's instructions.

Her study, unlike Schneider's, also looked at Latinos and Asians, for whom language barriers can further hamper communication.

But language doesn't explain everything, she said: in some categories, such as perceptions of disrespect, the problems were larger for African-Americans. Anecdotally, physicians and patients say that even seemingly small gestures - failing to shake patients'

hands or look them in the eye, not addressing them by name as "Mr." or Mrs." - can make an office visit go awry.

"If you have no confidence that your doctor has your best interests at heart, you're not going to follow the advice you receive or you're not going to go back," Collins said.

Such reasoning makes sense intuitively to many people, and some solutions seem obvious: The American Association of Medical Colleges is trying to recruit more minority physicians and make sensitivity training a more central part of medical school. But beyond that, it has been a challenge to find ways to measure and improve doctors' interactions with patients. Researchers say this is an inherently subjective and sometimes uncomfortable topic, since no doctor wants to believe he or she does not seem welcoming to someone of a different race, and few patients want to risk pointing it out.

But researchers around Boston are trying to make the discussion more concrete. At Brigham and Women's Hospital, Dr. Judy-Ann Bigby is holding focus groups between white male doctors and black female patients, to get them to talk honestly about their interactions. And Dr. Paula Johnson is studying patient evaluation reports by race for the first time in the hope they can be used for internal quality control; an important step, she said, is being willing to measure the problem and identify it as a priority of the institution.

At the same time, the authors of the Medicare study say the solution will lie beyond the behavior of individual doctors.

"There's a tendency to look at these sort of results and the first question is, well, are doctors prejudiced?" Schneider said. "You can ask that question, but a more useful question is what kinds of interventions can we put in place?"

Their study provides many of the tools to do that. It is the first to use data from government records that were designed in the mid-1990s specifically to measure the quality of health care delivery and that are widely accepted by hospitals and insurers. Those measures can later be used to test the success of attempts to improve the situation - such as outreach programs and patient education.

"We think it can make a difference," Schneider said.

Anne Barnard can be reached at abarnard@globe.com

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HARVARD GAZETTE ARCHIVES

Black Medicare Bias Found by Researchers

By William J. Cromie
Gazette Staff

Black Medicare patients in Illinois, New York, and Pennsylvania hospitals received poorer basic care than others treated for the same illnesses, according to a study by Harvard researchers.

The care included services such as medical history-taking, diagnostic tests, and standard drug treatments given to patients hospitalized with heart failure or pneumonia, the two most common causes of hospitalization for Medicare patients.
"Based on other research, ," according to John Ayanian, assistant professor of medicine and health care policy at Harvard Medical School.
The study revealed that only 32 percent of black pneumonia patients were given antibiotics within six hours of admission, compared with 53 percent of white and other Medicare patients. Also, blacks with pneumonia were less likely to have blood cultures done during the first two days of hospitalization. Other studies have associated prompt administration of antibiotics and collection of blood cultures with lower death rates.
"This study casts doubt on the idea that such racial disparities can be explained by patient preference," Ayanian and his colleagues say. Their study examined routine, low-risk noninvasive services unlikely to be refused by any patient. Prior research found that fewer blacks than whites undergo major medical procedure such as kidney transplants and coronary bypass surgery, raising the question of whether this occurs by choice.
"Our findings indicate that physicians, nurses, delivery system managers, and policymakers must continue striving to eliminate racial disparities in the quality of medical care," Ayanian comments.
The Harvard study, published in the December issue of Medical Care, also concluded that blacks receive better care at teaching hospitals than at other public or private hospitals because urban teaching hospitals provide better care to all patients. Even so, statistically adjusted results showed that blacks received poorer overall treatment for congestive heart failure and pneumonia.
These findings were based on reviews of medical records of almost 2,200 Medicare patients, 65 years and older, treated for heart failure and pneumonia at 501 hospitals in the three states in 1991 and 1992.
Asked if things may have changed since, Ayanian admitted that "we can't be sure. This is something that needs to be explored further." However, he and his colleagues were reasonably confident of their results because other studies of the disparity in health care between blacks and whites have not changed since 1992.
Ayanian says, "We now need to go beyond increased awareness and take specific actions to reduce the racial gap in health care."

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Revised Final FY 1999 Performance Plan And FY 2000 Performance Plan

XV. Eliminating Racial and Ethnic Disparities

Eliminating Health Disparities in Chronic Disease

The continuing disparities in the burden of death and illness associated with chronic diseases, such as cancer, cardiovascular disease, and diabetes, experienced by African-Americans, Hispanics, American Indians and Alaska Natives, and Asian-Americans and Pacific Islanders, compared to the U.S. population as a whole demands national attention. The health disparities associated with chronic diseases offers a compelling reason for addressing this issue. Examples of ethnic health disparities in chronic disease include:

- Diabetes - The prevalence of diabetes in African-Americans is approximately 70 percent higher than whites and the prevalence in Hispanics is nearly double that of whites.
- Cardiovascular disease - Racial and ethnic populations have higher rates of hypertension, tend to develop hypertension at an earlier age, and are less likely to undergo treatment to control their high blood pressure.
- Cancer - For men and women combined, African-Americans have a cancer death rate about 35 percent higher than that for whites (171.6 vs. 127.0 per 100,000). The death rate for cancer for African-American men is about 50 percent higher than it is for white men (226.8 vs. 151.8 per 100,000).

The demographic changes that will unfold over the next decades magnify the importance of addressing disparities in health status especially with regards to chronic diseases. CDC intends to address these three chronic disease issues as part of the President's Initiative on Race. Recognizing that the future health of the American people as a whole will be influenced substantially by our success in improving the health of racial and ethnic groups, CDC is committed to addressing the disparities associated with diabetes, cardiovascular disease, cancer and infant mortality through new and existing disease prevention and health promotion strategies.

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JAMA HIV/AIDS HIV/AIDS Resource Center
The Journal of the American Medical Association

Newsline

CDC National Center for HIV, STD and TB Prevention
Daily News Update: October 12, 2000
General Media

- Current CDC daily news index
- Index for week ending 10/13/00

CDC Commits to End Racial Disparities in Health Care
Reuters Health Information Services (www.reutershealth.com) (10/11/00)
The Centers for Disease Control and Prevention (CDC) has announced a $19 million award to 24 community health programs, as part of an effort to help end racial and ethnic health disparities. CDC Director Dr Jeffrey Koplan said the CDC wants to eliminate such health disparities by 2010. The grants are part of the agency's Racial and Ethnic Approaches to Community Health (REACH 2010) initiative, which targets HIV/AIDS, infant mortality, breast and cervical cancer, heart disease, immunization coverage, and diabetes. The funds will be distributed to programs in 15 states that assist African American, American Indian, Asian American, Hispanic American, and Pacific Islander populations.

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Fact Sheet

Addressing Racial and Ethnic Disparities in Health Care

The overall health of the American population has improved over the past few decades, but all Americans have not shared equally in these improvements. Among nonelderly adults, for example, 17 percent of Hispanic, and 16 percent of black Americans report they are in only fair or poor health, compared with 10 percent of white Americans.

How much do differences in the health care that people receive contribute to disparities in health? What strategies can overcome these differences in care? These are questions for health services research, and ones that researchers supported by the Agency for Healthcare Research and Quality (AHRQ, formerly the Agency for Health Care Policy and Research) have begun to address.

Identifying Disparities in Care

Access to Primary Care

Primary care is the underpinning of the health care system, and research studies have shown that having a usual source of care raises the chance that people receive adequate preventive care and other important health services. Data from AHRQ's Medical Expenditure Panel Survey (MEPS) reveal that:

- About 30 percent of Hispanic and 20 percent of black Americans lack a usual source of health care compared with less than 16 percent of whites.
- Hispanic children are nearly three times as likely as non-Hispanic white children to have no usual source of health care.
- African Americans and Hispanic Americans are far more likely to rely on hospitals or clinics for their usual source of care than are white Americans (16 and 13 percent, respectively, v. 8 percent).

Diagnosis and Treatment

Race and ethnicity influence a patient's chance of receiving many specific procedures and treatments. Of nine hospital procedures investigated in one study, five were significantly less common among African American patients than among white patients; three of those five were also less common among Hispanics, and two were less common among Asian Americans. Other AHRQ-

supported studies have revealed additional disparities in patient care for various conditions and care settings including:

- **Heart disease.** African Americans are 13 percent less likely to undergo coronary angioplasty and one-third less likely to undergo bypass surgery than are whites.
- **Asthma.** Among preschool children hospitalized for asthma, only 7 percent of black and 2 percent of Hispanic children, compared with 21 percent of white children, are prescribed routine medications to prevent future asthma-related hospitalizations.
- **Breast cancer.** The length of time between an abnormal screening mammogram and the followup diagnostic test to determine whether a woman has breast cancer is more than twice as long in Asian American, black, and Hispanic women as in white women.
- **Human immunodeficiency virus (HIV) infection.** African Americans with HIV infection are less likely to be on antiretroviral therapy, less likely to receive prophylaxis for *Pneumocystis* pneumonia, and less likely to be receiving protease inhibitors than other persons with HIV. An HIV infection data coordinating center, now under development, will allow researchers to compare contemporary data on HIV care to examine whether disparities in care among groups are being addressed and to identify any new patterns in treatment that arise.
- **Nursing home care.** Asian American, Hispanic, and African American residents of nursing homes are all far less likely than white residents to have sensory and communication aids, such as glasses and hearing aids. A new study of nursing home care is developing measures of disparities in this care setting and their relationship to quality of care.

Identifying that disparities in care exist is important, but it is not enough. Now, researchers are also beginning to focus on why these disparities exist, which disparities actually indicate poor-quality care, and how to develop strategies to address them.

Looking Beyond Income and Insurance

Disparities in health care are often ascribed to differences in income and access to insurance. Research has shown these to be important, but by no means the only factors. For instance, the proportion of Hispanic Americans with a usual source of care has declined substantially over the past decade (from 80 percent in 1986 to 70 percent in 1996). Insurance coverage has also declined, and the lack of insurance in some groups is dramatic (among Hispanic men, for instance, 37 percent have no health insurance). Nonetheless, declines in insurance coverage explained only one-fifth of the change in access to a usual source of care.

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In another recent study, AHRQ-funded researchers in Boston examined the quality of care provided to hospital patients with congestive heart failure or pneumonia. Quality of care was measured both by physician review and by adherence to standards of care. The researchers found no difference in quality of care for patients from poor communities compared with other patients, after adjusting for other factors. They did find, however, that African American patients received a lower quality of care than white patients.

Physician Decisionmaking

A small study of physicians' decisions about whether to refer patients for cardiac catheterization, a diagnostic procedure for heart disease, provides supportive evidence that factors other than insurance and income can influence the quality of care people get. This study, which used actors portraying similar economic backgrounds, found that black women were significantly less likely than white men to be recommended for referral, despite reporting the same symptoms. (Differences between other groups studied were not statistically significant.)

Hospital Characteristics

In the Boston study of the quality of care, quality for African American patients was lower in nonteaching than in teaching hospitals. In another study, white patients were more likely than Hispanic and African American patients to receive invasive cardiac procedures in hospitals performing a high volume of such procedures, a factor strongly associated with the quality of cardiac care.

Cultural and Communication Barriers

Adding to the increasing evidence of cultural expectations, assumptions, and language as factors affecting the quality of care, an ongoing study by AHRQ-supported researchers in San Francisco is surveying African American, Hispanic, and white patients to examine how interpersonal processes—the way patients and clinicians interact—affect the health care that patients get and the outcomes of their care.

Translating Research Into Practice

Supporting Evidence-based Decisionmaking

One way to begin to address disparities in the quality of care is to improve clinicians' abilities to apply the results of previous research to minority patients whenever relevant research exists. AHRQ supports tools such as the National Guideline Clearinghouse™ (http://www.guideline.gov) to give clinicians and other health decisionmakers better access to evidence-based information about diagnosis and treatment.

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Helping Patients Pursue High-quality Care

To support patient decisionmaking, AHRQ researchers and staff have developed numerous Spanish-language publications, including Spanish versions of:

- Consumer Assessment of Health Plans (CAHPS®). The CAHPS questionnaire provides survey-based assessments of consumers' satisfaction with their care and helps people select among health plans.
- Put Prevention Into Practice *Personal Health Guide* and *Child Health Guide*. These patient booklets help people track whether they or their children have received recommended preventive services.

Developing Better Strategies for Quality Improvement

AHRQ is currently supporting several research initiatives to develop new tools for improving the quality of care and new strategies providers can use to help them incorporate evidence into everyday practice. Several of these initiatives place a special emphasis on supporting research that can help address racial and ethnic disparities in health. In fiscal year 1999, AHRQ directed approximately $2 million towards this specific objective. In fiscal year 2000, this investment is expected to increase by $10 million, including:

- Funding for "centers of excellence" to develop practical tools in eliminating racial and ethnic disparities.
- Supporting research that involves partnerships between academic researchers and health care providers who serve predominantly minority communities.
- Supporting training for minority health services researchers to address the priorities identified in the President's Initiative to Eliminate Racial and Ethnic Disparities in Health.

Through such research, AHRQ can help close the gap between what we know and what we can do to address these disparities.
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